

**“Normal’s different for me now”:
A qualitative study of women’s experiences
of ending treatment for breast cancer**

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CONTENTS

Abstract	6
1. Introduction	7
1.1 Breast Cancer and Treatment	7
1.2 Models of Coping and Adjustment to Cancer	13
1.3 Breast Cancer ‘Survivorship’	17
1.4 Experience of End of Treatment	20
1.5 Research Context & Aim	28
2. Method	31
2.1 Research Methodology	31
2.2 Ethical Considerations	33
2.3 Participants	35
2.4 Research Procedure	38
2.5 Reflective Practice	42
2.6 Quality in Qualitative Research	43
2.7 Dissemination of Research Findings	44
3. Findings: Constructing a New Normal	45
3.1 Loss of Cocoon	47
3.2 Living with Uncertainty	51
3.3 Regaining Control	54
3.4 Re-defining Identity	59
3.5 Relationships	63
3.6 Personal Growth	67
3.7 Summary of Findings	70

4. Personal Reflection	71
5. Discussion	74
5.1 Constructing a New Normal	74
5.2 Methodological Considerations	78
5.3 Theoretical Implications	82
5.4 Clinical Implications	84
5.5 Future Research	87
5.6 Conclusion	88
6. References	89
7. Appendices	111
1 Invitation Letter	112
2 Participant Information Sheet	113
3 Participant Consent Form	115
4 Letter to Consultant & GP	116
5 Ethics Committee Approval	117
6 Research & Development Approval	119
7 Interview Guide	121
8 Sample of Transcription and Coding	122
9 Example of Early Diagram – Early Themes	128

ABSTRACT

Introduction: There is conflicting evidence in the literature regarding the experience of women ending treatment for breast cancer. Some research reports little discrepancy between women with breast cancer and the general population on measures of distress, anxiety, depression and quality of life. Other studies demonstrate that women experience disrupted adjustment and cancer-specific concerns following the end of their treatment. The aim of this study was to explore the subjective experience of women who had ended their treatment for breast cancer.

Method: Interviews were conducted with nine women who had ended treatment for breast cancer. Their accounts were recorded and transcribed verbatim, then analysed according to the principles of Constructivist Grounded Theory methodology.

Results: The results suggest that women attempt to construct a 'new normal' following the end of their treatment. Doing so involves women managing the loss of the hospital cocoon, regaining control, living with uncertainty, negotiating changes in their relationships and their identity and experiencing personal growth.

Discussion: The current results are discussed in relation to the existing theoretical and research literature, and methodological limitations are identified. In addition, possible implications for service delivery, clinical practice and future research are discussed.

1. INTRODUCTION

This introductory chapter aims to provide a rationale for the current study by presenting and discussing relevant background literature. The first section provides an overview of breast cancer, the available treatments, and their physical and psychological impact. The second section outlines theoretical models which are proposed to help our understanding of women's reactions to breast cancer. In the third section information is presented on the issues which face breast cancer survivors. The fourth section looks more specifically at literature regarding women's experiences at and around the end of treatment. The final section provides information about the research context and the rationale for undertaking this study, and outlines the current research aims.

1. 1 Breast Cancer and Treatment

Breast Cancer

Breast Cancer is the most common cancer in women and about 39,000 women are newly diagnosed each year in the United Kingdom (Ogden, 2004). Current data suggests that at least 1 in 8 women are likely to develop breast cancer within their lifetimes (American Cancer Society, 2006). Although the incidence is gradually increasing over time, the proportion of women dying from breast cancer is falling (ISD Scotland, 2007). Improvements in mammography screening and increased public awareness about symptoms of breast cancer mean more breast cancers are detected at an earlier stage (Gasparini *et al.*, 1993). This has improved survival rates, as have advancements in the treatment of breast cancer (Ganz *et al.*, 2004). This current study focuses on breast cancer in women, however it is important to be aware that, although rare, men can also have breast cancer (Ravandi-Kashani & Hayes, 1998).

Treatment of Breast Cancer

There are many effective treatments available for breast cancer. Decisions regarding which to use are dependent on a number of factors including the type and grade of

the disease, the cancer stage at diagnosis and patient choice. The Nottingham Prognostic Index (NPI; Galea *et al.*, 1992) is calculated using details of women's cancer at diagnosis (including tumour size, lymph node stage, and histological grade), and gives a prediction of prognosis. NPI scores tend to be divided into three categories indicating good, moderate or poor prognoses, and are used to decide women's individual treatment regimes (NHSBSP, 2005).

Surgery is often the first line treatment and can involve either mastectomy (removal of the entire breast) or lumpectomy (removal of the part of the breast where the tumour is located). In addition some ('axillary node sample') or all ('axillary node clearance') of the lymph nodes under the arms may be removed to help reduce the likelihood of the disease spreading (and detect if it has already spread).

Many women also receive adjuvant treatments, such as radiotherapy and chemotherapy, to reduce the risk of recurrence. These are given after surgery when as much as possible of the detectable disease has been physically removed. Radiotherapy uses ionising radiation to destroy any remaining cancer cells in the breast or chest wall thus reducing the risk of local recurrence. Chemotherapy uses cytotoxic drugs to eliminate any cancer cells throughout the body (Barraclough, 1999). Some patients will have had their cancer completely eradicated by primary surgery but there is no way to know this for certain. Adjuvant treatments are therefore for a risk rather than for a provable disease.

In addition to these active treatments, the many women who have cancers which are estrogen receptor positive ('ER positive') will receive hormone treatments. These come in the form of tablets, either Tamoxifen or another anti-estrogen agent, and are often taken daily for five years following treatment. Some women might also receive Herceptin treatment if they are one of approximately 20% of women who have tumours which impact the HER2 receptor. Herceptin is generally administered intravenously every three weeks over a year, again with the aim of reducing the risk of cancer recurrence (Piccart-Gebhart *et al.*, 2005).

Physical Side-effects of Breast Cancer Treatment

A number of side-effects from breast cancer treatments have been identified in the literature. Physical side-effects of surgery include pain, disfigurement, restricted movement and swelling in the arm (lymphedema) due to fluid retention (Bumpers *et al.*, 2002; Deimling *et al.*, 2002). The side-effects associated with radiotherapy include fatigue, skin and breast changes and pain, and shoulder swelling (Greenberg *et al.*, 1992; National Cancer Institute, 2000). Chemotherapy can also cause fatigue, nausea and vomiting, pain, hair loss, weight gain, peripheral neuropathy, concentration difficulties and menopausal symptoms (Costanzo, 2006; Rowland & Massie, 1998). Menopausal symptoms, especially hot flushes and sweats, can be exacerbated by hormone treatments. Tamoxifen can also cause joint pain, fatigue, weight gain and reduction in libido (Cella *et al.*, 2006; Mortimer *et al.*, 1999).

Psychological Reactions to Breast Cancer

Research shows that women with breast cancer commonly experience psychological distress (Mundy *et al.*, 2000; Nosarti *et al.*, 2002; Primo *et al.*, 2000). Emotions associated with diagnosis include anger, anxiety, low mood, shock, guilt and many more (Barraclough, 1999; Bennett *et al.*, 2006). These are all normal reactions to being diagnosed with a potentially life-threatening illness, and a period of increased distress termed an 'adjustment reaction' is expected (White, 2001). Degner *et al.* (2003) described diagnosis as a 'pivotal life event', where women are faced with philosophical questions about their own existence whilst trying to come to terms with the diagnosis (Cotton *et al.*, 1999; Edser & May, 2007; Landmark *et al.*, 2001).

Women also need to try to understand the medical information presented to them and make decisions regarding their treatment. This is often reported as being highly stressful for women, but can be beneficial in terms of their adjustment (Morris & Royle, 1988). However research has indicated that some women prefer to leave treatment decision-making to their doctors as they feel less able to retain information following the shock of their diagnosis (Beaver *et al.*, 1996). Women often feel frightened about recommended treatments, but are generally able to endure them as they want to take charge of their bodies and have the cancer removed (McQuellon *et*

al., 1995). Surgery, whether mastectomy or lumpectomy, is associated with high levels of distress and anxiety (Grandi *et al.*, 1987; van Herringen *et al.*, 1990) and can have a negative impact on body image and sexual functioning (Glanz & Lerman, 1992). People who receive chemotherapy and radiotherapy treatments report decreased psychological and social well-being (Blasco & Bayes, 1992; Campora *et al.*, 1992; Middleboe *et al.*, 1995; Moyer & Salovey, 1996). Hormone therapy can also have an impact on mood.

Undergoing treatment for breast cancer has a marked impact on how women spend their day to day lives. Attending hospital appointments and following treatment regimes often means that women are unable to continue with employment (Bouknight *et al.*, 2006). Their activity levels are generally reduced and as such their roles in the home might change, with other family members and friends assuming more of their responsibilities (Meyerowitz, 1980). This may result in women experiencing difficulties and disruptions in their inter-personal relationships (Northouse *et al.*, 1998; Schou *et al.*, 2005). Concerns relating to body image and sexual dysfunction can impact negatively on women's self-esteem and their marital relationships (Anderson, 1986; Irvine *et al.*, 1991). This can be especially difficult to cope with as serious illness tends to increase patients' needs for closeness to and support from others to counteract their feelings of vulnerability and fear of abandonment (Rowland & Massie, 1998). Women who receive better social support are found to have better mood and emotional adjustment, and also experience increased hope for the future (Devine *et al.*, 2003; Ell *et al.*, 1992). Harvey (2005) draws attention to the guilt women often feel in imposing additional stress and burden on family and friends, and the problems inherent in eliciting their support.

In addition to threatening women's sense of safety and personal control, cancer can often threaten women's sense of self-worth and personal identity (Cole & Pargament, 1999). Women experience changes to their relationships, valued goals, physical health and appearance, which may be key components of how they see themselves. Women often struggle with a loss of self-confidence and sense of purpose and meaning at some time during their cancer treatment (Kaufman & Micha, 1987).

Having breast cancer also activates women's existential concerns about isolation, death and life's meaning (Classen *et al.*, 2008; Yalom, 1980).

A number of other variables have been studied in relation to how they influence women's adjustment to breast cancer. Although these cannot be explored in detail here, it is important to be aware that they are likely to have an impact on women's experiences. These variables include personality, coping styles and lifecycle stage at which breast cancer diagnosis occurs, previous emotional stability and prior personal association with breast cancer (Rowland and Massie, 1998). In addition, research has shown that women's quality of life can be affected by their treatment, marital status and economic status (Ashwing-Giwa *et al.*, 2006; Broeckel *et al.*, 2000; Shimosuma *et al.*, 1999). Also feelings of self-efficacy and coping are associated with lower levels of depression and anxiety, and better well-being (Barez *et al.*, 2007; Watson *et al.*, 1999). In addition, women's satisfaction with their health care and communication with their doctors, have also been found to be predictive of their psychological well-being (Bettencourt *et al.*, 2007; Walker *et al.*, 2003).

It appears that age can also play an important role in affecting women's experience of coping with breast cancer (Danhauer *et al.*, 2007). In a large study of people with different types of cancer, it was noted that younger people and women reported most ongoing concerns (Baker *et al.*, 2005). Another study by Ganz *et al.* (2003) showed that younger women with breast cancer report higher levels of depression, fatigue, difficulty with body image and sexual dysfunction than their older counterparts. Possible reasons why younger women experience higher distress may be the premature onset of menopause, infertility issues, increased risk of disease recurrence, lack of spouse, career interruption and having young children (Dunn & Steginga, 2000; Anders *et al.*, 2008). Women might find changes in family dynamics and having decreased roles and responsibilities for their children particularly difficult to cope with (Thewes *et al.*, 2004; Walsh *et al.*, 2005).

It is clear from the above literature that a number of factors can influence women's psychological reactions to breast cancer, and that women may experience a range of

difficulties during their subsequent treatment. A meta-analytic review of 58 studies found that, compared to a healthy population, cancer patients showed somewhat higher levels of depression (van't Spijker *et al.*, 1997). However, not all women diagnosed with breast cancer go on to develop psychological difficulties. Estimates of the prevalence of clinically significant levels of distress, namely anxiety and depression, among breast cancer patients range from 33% to 45% of women (Kissane *et al.*, 1998; Zabora *et al.*, 2001). It is important that medical staff who work with women with breast cancer are able to identify these psychological problems, and offer appropriate support and treatment for them (Iconomou *et al.*, 2004; SIGN, 2005). Research has shown that anxiety and depression associated with breast cancer can affect women's compliance with their treatment regimes (Zabora *et al.*, 2001). These feelings are also linked to deficits in immune functioning that can have negative implications for survival (Kiecolt-Glaser *et al.*, 2002; Walker *et al.*, 2003).

It is, however, important to note that women do not experience solely negative psychological reactions to breast cancer. In an interview study three quarters of breast cancer patients reported both positive and negative life changes, such as concurrently seeing the self as stronger but also feeling more vulnerable (Collins *et al.*, 1990). It was identified that negative changes were outnumbered by positive ones in personal relationships and choice of daily activities, which were the life domains rated as the most amenable to personal change. Aspinwall & MacNamara (2005) found that positive life changes were identified in all the domains they studied which included views of the self, relationships, activities and priorities, views of the world and plans for the future. It has been proposed that these positive experiences and feelings are helpful in providing people with constructive ways to cope with their experience of cancer.

Summary of Section

Advances in breast cancer detection and treatment mean that more women diagnosed with the disease are experiencing positive treatment outcomes in terms of survival. However, the majority of women still experience a period of distress following diagnosis, which is viewed as a normal process in their adjustment reaction. Women

are faced with a number of challenges, both physical and psychological, whilst undergoing treatment for breast cancer. Women can experience different reactions to these challenges, with some going on to develop psychological difficulties and others finding positive outcomes. Theoretical models of coping and adjustment offer useful perspectives on how women respond to diagnosis and treatment, and will be presented in the following section.

1.2 Models of Coping and Adjustment to Cancer

This section gives an overview of theoretical models which aid our understanding of how women respond to the experience of breast cancer. A general model of stress and coping and two models of adjustment to cancer will be considered.

Cognitive Model of Stress and Coping

Folkman (1997) proposed a revised version of cognitive mediational models of stress (Lazarus, 1966; Lazarus & Folkman, 1984), which focuses on two key processes of appraisal and coping. Appraisal involves an individual's evaluation of whether or not an event is viewed as a threat, and also whether they think they can exert control over, or cope with, the event. This appraisal influences both how individuals feel about the event and how they subsequently cope with it. Coping can take three different forms; emotion-focused coping refers to the behaviours and thoughts the individual employs to regulate their distress; problem-focused coping refers to what the individual does to manage the problem; and meaning-based coping relates to strategies used by the individual to maintain positive well-being (Folkman, 1997). Coping can then influence the outcome of the situation, which in turn can then alter the individual's appraisals of it (Folkman & Greer, 2000). Meaning-based coping is often employed when other coping attempts have proved unsuccessful and it helps the individual to re-formulate their goals to something achievable, process what is happening to them and, if possible, try to find benefit within the event (Park & Folkman, 1997). By generating positive feelings the individual experiences some time away from their sense of distress, which facilitates the coping process. Both positive and negative feelings can occur in close succession to one another, with the

individual often oscillating between the two as they continue to manage the stressful event (Folkman, 1997). See Figure 1 for a representation of the model.

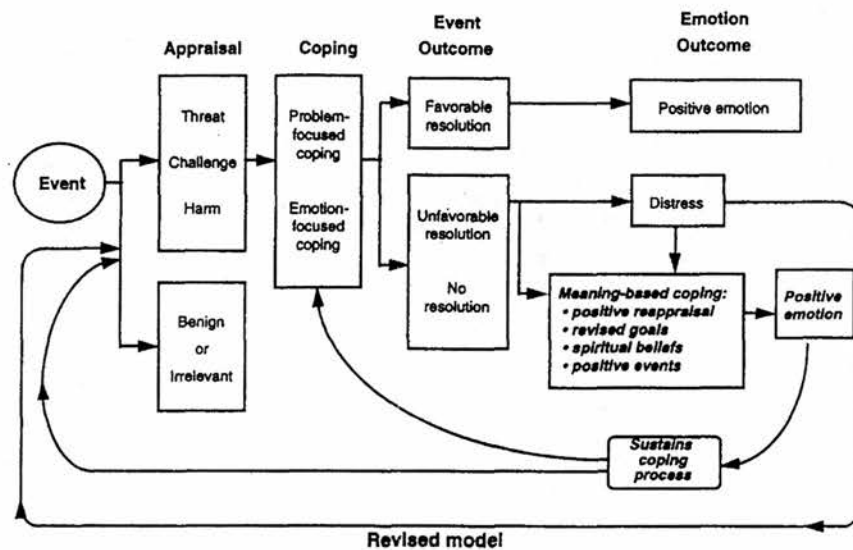


Figure 1: Revised Cognitive Mediation Model of Stress (Folkman, 1997, p1217)

This model describes different types of coping responses women might have to breast cancer, and highlights that these can change over time, depending on the meaning women make of their experience. It also accounts for the fact that women can experience both positive and negative emotions. When women are first diagnosed, many are likely to appraise breast cancer as a threat they feel unable to cope with or control. After the initial shock some women might find that having treatment (problem-focused coping) helps them to feel more positive, others might also employ distraction or social support to help them (emotion-focused coping), and yet other women might continue to experience distress. Thinking positively, or having spiritual beliefs, could help some women to cope with their situation (meaning-based coping).

Cognitive Model of Adjustment to Cancer

Moorey and Greer (2002) have developed a cognitive model of psychological adjustment to cancer. Their model draws on ideas from Lazarus and Folkman's (1984) model of stress and coping, and Beck's (1967, 1976) cognitive model of

depression. It is believed that individuals' early experiences lead them to develop core beliefs and assumptions about themselves, others and the world (known as schema). Stressful situations, which might remind individuals of the circumstances responsible for their beliefs, are likely to activate negative schema. Greer *et al.* (1992) propose that, in cancer patients, stressful situations not only activate these long-standing negative schema, but also trigger the production of survival or disease schema. These schema are the result of the individual's cognitive appraisal of their illness, prognosis and treatment, and can lead to the production of negative automatic thoughts. Therefore in this model psychological distress is viewed as an outcome of the dynamic interaction between the individual's negative core schema and their beliefs about their cancer (Moorey & Greer, 2002). The individual's negative automatic thoughts impact upon their emotions, physiology and behaviour which in turn leads to further confirmation of negative thoughts. See Figure 2 for a diagrammatic representation of Moorey & Greer's (2002) model.

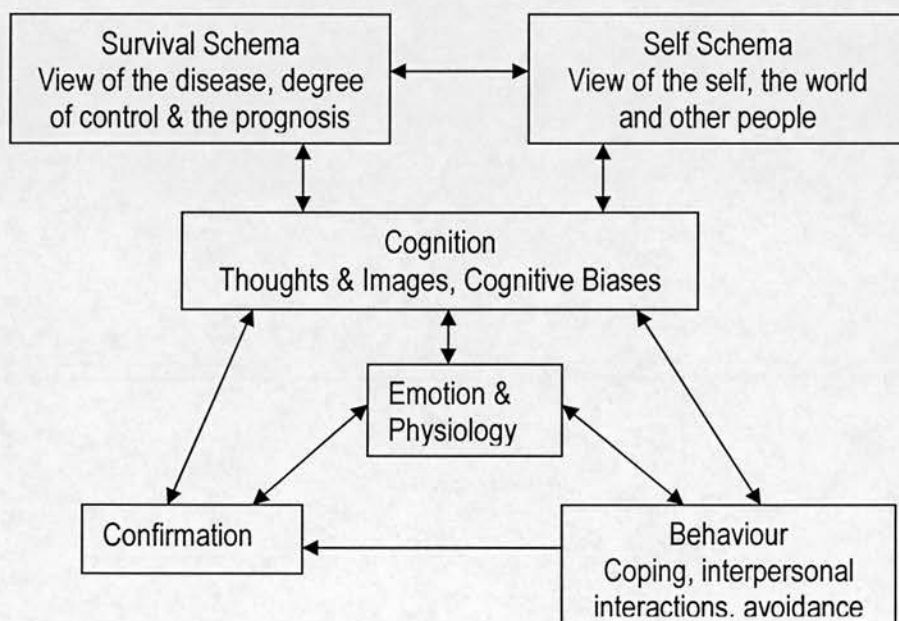


Figure 2: Cognitive Model of Adjustment to Cancer (Moorey & Greer, 2002, p20)

By incorporating the role of individual beliefs, both related to life in general and cancer, this model offers an explanation as to why women experience different reactions to breast cancer. It also suggests possible mechanisms for change for women who experience distress, for example through challenging cognitive biases.

Social-Cognitive Transition Model of Adjustment

Brennan (2001) argues that an adequate model of adjustment to cancer needs to be able to account for both the positive and negative ‘adjustments’ that people go through. He proposes the Social-Cognitive Transition (SCT) model of adjustment which brings together concepts from coping theory and social-cognitive theory (see Figure 3 for a diagram). The suggestion is that ‘psychologically shocking events’, such as a diagnosis of cancer, can overwhelm an individual’s mental model of the world including all their assumptions about how the world should be. The individual will then experience a disrupted time, with periods of distress and denial, as they try to modify their core assumptions. Brennan proposes that the core assumptions which require modification after cancer diagnosis are an individual’s personal life trajectory, beliefs about self-worth and control, nature of their attachments and spiritual/existential beliefs. Re-evaluation of each of these assumptions can lead to either positive or negative transitions. The SCT model of adjustment is a ‘model of normal adaptation’, which allows it to incorporate a wide variety of experiences (Brennan, 2001, p 14). Brennan notes that:

“adjustment is not simply the end-point of an individual’s cancer journey but, rather, an active psychosocial process which may include both positive and negative consequences for the individual and which may contain the seeds for the later development of psychological disorders and interpersonal problems” (2001, p14/15)

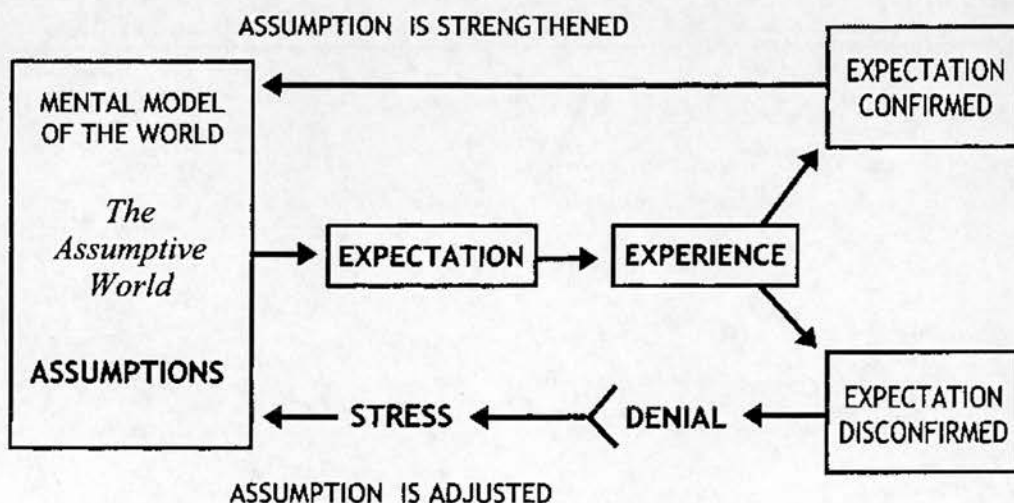


Figure 3: Social-Cognitive Transition Model of Adjustment (Brennan, 2001, p8)

Summary of Section

The models outlined above provide helpful conceptual frameworks for understanding how women experience breast cancer. They demonstrate that coping and adjustment are active ongoing processes, which are affected by women's individual characteristics and appraisals of the situation. As such, they help explain why some women experience psychological difficulties in response to breast cancer and others do not. These models do not, however, provide information regarding a time frame within which women may continue to have difficulties.

1.3 Breast Cancer 'Survivorship'

It is important that we aim to understand and optimise the quality of women's lives following breast cancer (Bettencourt *et al.*, 2007). As outlined earlier improvements in breast cancer detection and treatment mean that the majority of women (approximately 85%) are surviving at least five years post-diagnosis (American Cancer Society, 2006; Imaginis, 2005). In fact, due to improved survival rates it is now thought that cancer is best conceptualised as a chronic disease (White, 2001). As such, it has been suggested that survival is not the only valid outcome measure of breast cancer treatment, and that psychological welfare should be taken in to account.

There is some debate regarding the terms 'survivor' and 'survivorship' in the breast cancer literature. Some researchers classify a 'survivor' as women who have lived at least five years following their diagnosis, whereas others believe women to be surviving from the moment they have been diagnosed. For the purpose of this section of the introduction, the term 'survivor' refers to women who have long-finished their treatment for breast cancer.

There is mixed evidence regarding the experience of breast cancer survivors. Much research has drawn attention to the fact that women experience reduced quality of life, well being and physical functioning when compared to individuals who have never had cancer (Baker *et al.*, 2003; Gotay & Muraoka, 1998).

Ongoing physical concerns reported in the literature include pain, fatigue, early menopause, loss of fertility, weight gain, insomnia, osteoporosis and lymphedema (Beisecker *et al.*, 1997; Bower *et al.*, 2006; Bumpers *et al.*, 2002; Kornblith *et al.*, 2003). Breast cancer survivors also continue to experience difficulties with the loss of their breast, body image and sexual functioning (Ganz *et al.*, 1996; Meyerowitz *et al.*, 1999). Mild cognitive impairment also continues to be problematic for about a third of survivors post-chemotherapy (Ahles *et al.*, 2002; Jenkins *et al.*, 2006; Schagen *et al.*, 1999).

There is evidence that a significant proportion of women's psychological difficulties may persist for several years after treatment is finished (Dorval *et al.*, 1998). Some studies have shown increased levels of anxiety and depression (Saleeba *et al.*, 1996) and decreased quality of life in breast cancer survivors (Baker *et al.*, 2003). Other research has suggested that women's levels of distress are more similar to those found in the general population (Kurtz *et al.*, 1995).

In a review of the literature regarding adjustment in women with breast cancer, Moyer and Salovey (1996) concluded that older studies showed higher levels of anxiety and depression in breast cancer survivors, whereas studies which were more recent indicated that women's levels of distress were more in line with those in the general population. Further research has found no differences between breast cancer survivors and the general population on measures of depression, health-related quality of life, marital and sexual functioning (Ganz *et al.*, 1998; Helgeson & Tomich, 2005). A recent review by Mols *et al.* (2005) has also concluded that survivors of breast cancer report similar quality of life to members of the general population who have not had cancer. In another study, breast cancer survivors rated their overall long-term quality of life as fairly high, and many of them identified positive changes as a result of their cancer experience (Leedham & Ganz, 1999).

There has been suggestion in the literature that it might be helpful to conceptualise survivors' experiences of cancer within a post-traumatic stress framework (Andrykowski *et al.*, 1998; Smith *et al.*, 1999). It has been shown that cancer

survivors can experience intrusive thoughts and nightmares, avoidance of painful reminders of cancer, increased arousal and a loss of sense of being invulnerable (Alter *et al.*, 1996; Hassey Dow, 1990; Kangas *et al.*, 2002). Although only between 3% and 10% of cancer survivors are thought to meet criteria for the diagnosis of post-traumatic stress disorder (Cordova *et al.*, 1995; Gotay & Muraoka, 1998) it is thought that almost half of cancer survivors experience some of the symptoms (Alter *et al.*, 1996; Andrykowski *et al.*, 2000).

Anxiety, depression, quality of life and post-traumatic stress are important constructs to consider when investigating survivors' experiences. However it is likely that breast cancer will affect women's lives in more ways than just impacting on their self-reported scores on measures of distress. These measures are unlikely to detect any cancer-specific issues. Ferrell *et al.* (1997) draw attention to the fact that cancer survivors experience symptom-related distress and cancer-related worries including fear of recurrence, concern about death and worry about the impact of cancer on their families. Survivors may also struggle to adjust to some amount of physical compromise and find it hard to manage in their home and work community (Welch-McCaffery *et al.*, 1989).

Ashwing-Giwa *et al.* (2006) conducted focus groups with Latina women who had finished their breast cancer treatment on average 4 years previously. They identified a number of concerns amongst the women including fears about recurrence, concerns about maintaining employment and worries about changed femininity and body-esteem. However they also noted that women felt more spiritual, had good support from family and took more care of themselves and their health.

In another qualitative study individual interviews were conducted with survivors of numerous cancer types, who were more than five years post-diagnosis (Foley *et al.*, 2006). They investigated how survivors interpret their cancer experience and identified that deriving meaning is an important part of adjustment. The four major themes that emerged from interviews were 'personal growth', 'that's life', 'resentment' and 'relinquishing control'. It was noted that the majority of survivors

were able to make positive adjustments after cancer treatment either by using the experience to make their lives better ('personal growth') or by incorporating it into their lives in a 'matter-of-fact manner' ('that's life'). Resentment was said to be identified in survivors who continued to experience ongoing psychological distress or physical problems. Although Foley *et al.* (2006) did not find differences in themes in survivors of different cancers, they did note that women were more likely to express a greater appreciation for life than men, and aimed to have a more fulfilling existence through volunteer work.

Other research has shown that there is a tendency for breast cancer survivors to volunteer more in the long-term following treatment (Coggin & Shaw-Perry, 2006; Wyatt *et al.*, 1993). Also in an interview study with long-term female cancer survivors, Wyatt & Friedman (1996) found that some women focused more on their relationships and existential issues after their cancer experience, giving them some perspective about the physical changes they had sustained.

Summary of Section

Although there is debate in the literature about the extent to which breast cancer survivors experience psychological distress in the years after their treatment has ended, it is clear that they continue to face some difficulties. In order to understand how these difficulties persist following diagnosis and treatment, it is helpful to explore the trajectory of distress in women with breast cancer from diagnosis onwards.

1.4 Experience of End of Treatment

Studies measured from Diagnosis

In a study of women with early-stage breast cancer, Stanton *et al.* (2002) reported that self-reported mood disturbance decreased from diagnosis to 3 months post-surgery and again at 12 months post-surgery. Other research supports this trend of a decline in distress from diagnosis (Glanz & Lerman, 1992; Irvine *et al.*, 1991). In contrast to this, some research has shown that while positive changes were observed

in women's health and physical functioning both 4 and 10 months on from diagnosis, there were no improvements in well-being and mental health (Vinokur *et al.*, 1990). When adjustment was measured at 3, 6, 9 and 12 months post-diagnosis by Ell *et al.* (1989), they found that the mental health of women with breast cancer deteriorated.

There are some methodological aspects which impact on the extent to which these studies are helpful. The older studies are likely to be less relevant now due to improvements in treatment, prognosis, after-care and awareness of psychological issues in recent years. Costanzo (2006) draws attention to the fact that research teams use different measures of different constructs, which makes their results difficult to compare. Also these studies asked women to complete measures at specific time periods after their diagnosis, which makes it impossible to know which stage of treatment women were at, and makes it unlikely that women were at the same stage as one another due to individualised treatment plans (Leedham & Ganz, 1999). This means it is difficult to assess the impact of any specific events, such as the end of treatment. Another possible methodological problem is that these studies all use diagnosis as a baseline for assessing distress in women with breast cancer. Although the practical reasons for doing this are understandable, it is not ideal as diagnosis is often a disrupted and upsetting time for the majority of women with breast cancer (Frost *et al.*, 2000; Osowiecki & Compas, 1999; Stanton & Snider, 1993).

Studies using End of Treatment as reference point

Research that specifically uses the end of adjuvant treatment as a reference point is more helpful when trying to understand women's experiences of this time. Ward *et al.* (1992) conducted a review of the literature on women's reactions to ending adjuvant treatment. They found that distress decreased from first chemotherapy treatment to the end of chemotherapy treatment, and then decreased further at 6 months post-treatment. Despite this overall decrease, 71% of women reported experiencing anxiety, depression or emotional problems just after ending their chemotherapy. Ward *et al.* (1992) also found that 30% of the women in their study reported finding the termination of their treatment upsetting.

Other longitudinal studies have suggested that anxiety and depression may increase for women with breast cancer after ending their treatment (Culver *et al.*, 2002; Walker *et al.*, 1996). A study examining depression after chemotherapy for breast cancer found that 10% of women met the diagnostic criteria for major depressive disorder at their first follow-up appointment (Morasso *et al.*, 2001). However this figure does not differ significantly from naturally occurring rates of depression in the general population, so it does not provide specific information about the end of treatment.

Deshields *et al.* (2005) investigated psychological adjustment and quality of life in women who had completed radiotherapy treatment for their breast cancer. Measures were completed at the end of radiotherapy and then 2 weeks, 4 weeks, 3 months and 6 months post-treatment. The results showed that at the end of treatment, women were experiencing increased levels of depression and reduced quality of life, but low levels of anxiety. Two weeks later depression scores had decreased significantly, and there had been a significant increase in overall quality of life. However despite this overall improvement in scores, approximately 25% of women consistently scored above the cut-off for depression at every time point, suggesting ongoing depression in this subgroup of women. Deshields *et al.* (2005) also reported their surprise that levels of anxiety were not elevated at the end of treatment, as this ran contrary to their expectations and prior research in the literature. They found no further changes to levels of distress or quality of life in the later follow-ups.

A later study focused specifically on assessing women's symptoms in the six months following the completion of breast cancer treatment (Deshields *et al.*, 2006). They identified that women experienced different patterns of depressive symptoms during this six months, with some showing a decrease in symptomatology over time whilst others showed an increase. Overall, 30% of women at some point reported depressive symptoms that would place them in the range of clinically significant depression. However, the researchers draw attention to the fact that the largest group of women were those that had never been depressed at any time point, which leads them to conclude that 'resilience' is the most common response to breast cancer.

This, however, implies that being resilient and being depressed are mutually exclusive, which is not necessarily the case. It also does not explain what factors influenced women's individual patterns of depressive symptoms in the months following treatment.

Costanzo (2006) investigated distress, quality of life, health-behaviour change and life-stressors in women finishing adjuvant treatment for breast cancer (chemotherapy or radiotherapy). Measures were completed at the end of treatment and both 3 weeks and 3 months post-treatment. It was concluded that women were well-adjusted following treatment, with low levels of anxiety and depression, and health-related quality of life that was comparable with population norms. There were no significant changes in these measures of distress over time. Women did, however, report significant concerns which were not picked up by these traditionally used measures. These included concerns about ongoing physical symptoms, fears of recurrence and managing the process of trying to get back to normal. Women also noted increased health behaviours following the end of their treatment including reduction in smoking, increased frequency of breast examination, increase in fruit and vegetable consumption and a reduction in alcohol intake.

These findings support those of Beisecker *et al.* (1997) who interviewed women at the end of their chemotherapy treatment and again six months later. The main concerns raised at the initial interview were fatigue, treatment-related problems, nausea and hair loss. Six months later women most often reported fatigue, menopausal problems, weight gain, hair and nail problems and emotional problems. The majority of women had not expected to still be experiencing breast cancer treatment-related problems, which interfered with their daily lives, six months after ending their chemotherapy (Beisecker *et al.*, 1997).

Interview studies are helpful in this area of research as cancer-specific forms of distress among women might not be picked up by studies employing standardised questionnaire methods (Ferrell, 1997; Rabin, 2003). Research has also shown that longitudinal assessment of mental health and quality of life in people with health

problems can be biased by response shifts caused by changes in internal standards and values (Schwartz *et al.*, 2004).

The End of Treatment

Breaden (1997) called for the need to study individual perspectives of the phenomenon of ending treatment for cancer. Although research of this period is rather scarce, there are some interesting personal accounts of difficulties after ending cancer treatment available. Some of these have been written by doctors who have also had an experience of cancer, and they have been clear about the distress which they experienced following the end of their treatments (McKinley, 2000; Mullan, 1985; Schnipper, 2001). For example, Mullan (1985) describes the lack of regular medical contact after treatment as a “void that leaves many cancer patients and their families fending awkwardly for themselves in the ‘healthy’ world” (p272). Qualitative research offers the opportunity to gain a rich understanding of individual experiences and investigate the phenomenon fully.

A number of reasons for why ending treatment might be difficult have been identified in the literature. Lethborg *et al.* (2000) identified that some women feel ‘cast adrift’ by the medical system when they end treatment as they have reduced contact with their doctors and nurses. Although women can be relieved to be finished the often physically unpleasant treatments, they can also feel they are losing the ‘safety net’ of actively treating or ‘fighting’ their cancer, and thus are losing a helpful coping strategy (Beisecker *et al.*, 1997; Culver *et al.*, 2002; Ward *et al.*, 1992). The safety associated with treatment is replaced by a sense of doing ‘nothing’ after active treatment is finished (Dodd *et al.*, 1993) despite taking hormone tablets. Spending less time attending medical treatments and hospital appointments reportedly leaves people with more time to confront and reflect on the psychological aspects of their cancer (McQuellon *et al.*, 1998; Schnipper, 2001; Thewes *et al.*, 2004). SIGN (2005) draws attention to the fact that there are significant variations between women’s experiences of the support they receive from professionals. They reported that “some found their GP and Breast Care Nurse a great source of support while others felt abandoned and isolated without knowing whom to contact” (SIGN, 2005, p33).

Lethborg and Kissane (2003) found that women became more aware of the reality of their cancer diagnosis after their treatment ended and began to contemplate their existential fears at this time. Other research has also found that women were vulnerable to anxiety about their cancer after the end of treatment, and reported uneasiness about being on their own (Holland & Reznik, 2005). Fears of cancer recurrence are common at this time (Baker *et al.*, 2005; Stanton *et al.*, 2005). These fears focus on threats to future health, further treatment and the possibility of death (van den Beuken-van Everdingen *et al.*, 2008; Vickberg, 2003). Women are also confused at this time regarding their cancer 'status', and whether they have been 'cured' or not (Costanzo, 2006). Women also continue to experience uncomfortable physical side-effects, and are often surprised at how long these last (Beisecker *et al.*, 1997; Stanton *et al.*, 2005). Higher levels of self-reported physical symptoms at the end of treatment are associated with poorer physical and emotional well-being, so need to be properly monitored and treated (Ganz *et al.*, 2004).

Women often seem unprepared to experience difficulties at this time, having anticipated the end of treatment being a time of celebration. In addition, family and friends do not always appreciate that women have ongoing needs for support and help at this time, expecting things to go 'back to normal', which can leave women feeling even more confused by their feelings (Schnipper, 2001; Van der Molen *et al.*, 2004; Vinokur *et al.*, 1990). On the other hand, some family and friends become too overprotective of women after their breast cancer treatment, which leaves them feeling incapable and as if others view them as an 'invalid' (Holland & Reznik, 2005). Women who do accept offers of help can feel abandoned and isolated by family and friends if these are not carried through, which makes them less likely to request help from others (Chantler *et al.*, 2005). As such, women often have to put on a 'brave face' for family members, who are happy that the treatment is over.

Chantler *et al.* (2005) conducted focus groups with women who had been treated for breast cancer. They identified that other breast cancer survivors were viewed as a good resource for both emotional and information support. It would seem that sharing experiences with one another helped provide both advice and a sense of

camaraderie. Women have also been found to access fellow patients' stories on the internet after treatment, to find out how to cope with emotions, physical problems and the impact of cancer on daily life (Overberg *et al.*, 2007). It seems that the sense of only being fully understood by other cancer patients can contribute to women finding it hard to get a balance between being treated as normal and wanting to be seen as a cancer patient. This uncertainty can make it difficult for women to try to 'get back to normal' after their treatment (Berard, 2001). Women might also make significant life changes at this time, as they realise they do not want to, or are unable to, return to their 'pre-diagnosis selves' (Fobair *et al.*, 1986).

Breaden (1997) interviewed six women, who had experienced different types of cancer, and were all finished their active treatment and were approximately 8 months post-diagnosis. She identified two main concepts of the survivorship experience of these women; 'living in a body' and 'living in time'. Living in a body incorporated themes of 'feeling whole', 'from an experience of disembodiment to embodiment' and 'the body as a house of suspicion'. Themes within living in time included 'changes in time', 'the future in question', 'lucky to be alive' and 'sharing the journey'.

As Brearden (1997) suggests, there is evidence that women might find benefit in the experience of ending, and having undergone, treatment for cancer (Brennan, 2001; Sears *et al.*, 2003, Tartaro *et al.*, 2005; Taylor, 2001). Allen *et al.* (2008) conducted focus groups with women to explore their transition from breast cancer 'patient' to 'survivor'. Their results suggested that women experienced positive life changes as a result of the cancer experience. Women also reported a number of stresses at this time including fear of recurrence, emotional distress, losses associated with the end of treatment and difficulty returning to 'normal' life.

Stanton *et al.* (2005) have proposed a framework for conceptualising post-treatment adjustment based on their research in the area. They propose that women's context (individual, environmental and disease-related) impact on how they appraise and cope with the end of their treatment. This then has an effect on four key domains of

their lives; emotional functioning, physical functioning, interpersonal relationships and life perspectives. Stanton and colleagues believe there are common myths about completing treatment which hinder women's adjustment at this time. These are; 'I should be celebrating', 'I should feel well', 'I should be the pre-cancer me' and, 'I should not need support'. Women then need to undertake adaptive tasks when their experiences in the four domains do not match with these pre-conceived ideas. See Figure 4 for a diagram of their model for post-treatment adjustment.

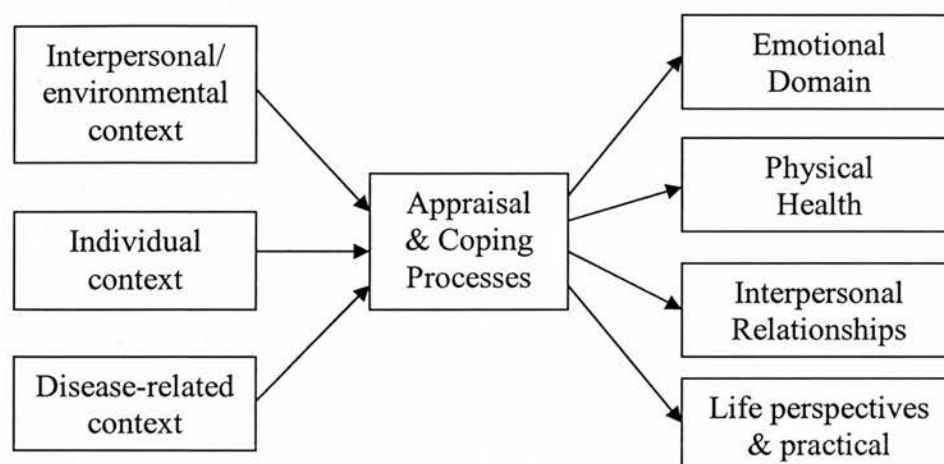


Figure 4: Framework for Post-Treatment Adjustment (Stanton et al., 2005, p2611)

This model provides a helpful conceptualisation of the experience of ending treatment. It demonstrates that women experience specific difficulties associated with ending treatment, rather than just viewing problems at this time as those continuing from the time of diagnosis. However it would be helpful to have more detailed information about the types of concerns women express within these four life domains.

Summary of Section

Women continue to experience some difficulties following treatment for breast cancer. Some women have depression, anxiety and post-traumatic stress symptoms, although the extent of these difficulties is difficult to ascertain due to some methodological complications with the research. Many studies investigate these constructs in isolation rather than trying to understand the overall experience of

ending treatment. Qualitative research offers the opportunity to gain more insight into this time from women's perspectives. A systematic qualitative study of women's experiences after ending treatment for breast cancer would be a valuable contribution to this literature.

1.5 Research Context & Aim

This final section outlines the research context for this study, the current service provision for women ending their treatment for breast cancer and the aims of this study.

Research Context – Local Service

The current research was undertaken in a regional Breast Unit based in the Cancer Centre of a general hospital. Women are referred to the Breast Unit via their GP or the local Breast Mammography Screening Service for investigations, diagnosis, treatment and follow-up.

At diagnosis women are assigned a named Breast Care Nurse Specialist (BCNS) as recommended in the SIGN Guidelines (2005). The role of the BCNS is defined by the Royal College of Nursing (2002) as “to provide information, physical and psychological care and give practical advice to patients and carers from diagnosis to treatment, rehabilitation and beyond”. The local BCNS team identified that women at the Breast Unit need specific support at the following stages in their ‘patient journey’; diagnosis, treatment decision making, beginning and end of treatment, and recurrence and disease progression (Gardner, 2005; Taylor, 2004). An evaluation of their practice in 2005 identified that there was a gap in supportive care provision for women at the end of their treatment (Calder, 2005).

The BCNS team, in collaboration with the Oncology Physiotherapy team, developed a drop-in ‘End of Treatment Group’ to meet this need. The group, which is run every two months, provides women with the opportunity to share their experiences with other women in the same position and receive advice and support from the clinical team. Women are also reminded how to access the wide range of support services

available to them including charitable organisations like Maggie's Centre, Breast Cancer Care, CancerBACUP and Reach for Recovery. Women can also be referred on to the Clinical Psychology Service to Oncology for therapeutic intervention if they are identified as experiencing significant psychological distress (Gardner, 2005).

In my role as a Trainee Clinical Psychologist I was requested to undertake an audit of the End of Treatment Group service (Forrester, 2006). The results indicated that women found the group very helpful, and felt it was most beneficial for them to attend between 1 and 6 months post-treatment. The most commonly reported hopes for attending the group were 'opportunity to ask about specific medical concerns', 'advice/information about exercise' and 'support from other women who have had treatment'. Women endorsed that these were indeed the most beneficial aspects of the group. These findings were backed up in the literature, where research has shown that women with breast cancer benefit from attending groups as they can share a 'bond of common experience' (Dunn *et al.*, 1999), receive support and advice from other group members (Docherty, 2004) and also have the opportunity to compare themselves with others in similar situations to help normalise their feelings and experience (Dunn & Steginga, 2000). Whilst undertaking this audit it was agreed with the BCNS and Physiotherapy teams that I should become a co-facilitator in the Group in order to provide a psychological perspective.

Further to the success of the 'End of Treatment Group' a six-week exercise and relaxation group for women who have ended their breast cancer treatment has been established by the Physiotherapy team. The aim of this group is to help women regain their confidence in exercising and improve their fitness. Research has shown that breast cancer survivors who exercise regularly experience reduced fatigue and an improvement in their mood and quality of life (Hewitt *et al.*, 2005; Kendall *et al.*, 2005; Rabin *et al.*, 2008), with approximately one-third of breast cancer survivors starting a new physical activity (Patterson *et al.*, 2005).

Rationale for Current Research

As a Flexible Trainee Clinical Psychologist I spent three years working in a Clinical Psychology in Oncology Service, primarily working with women with breast cancer. My involvement in the 'End of Treatment Group', in addition to my direct therapeutic work, sparked my interest in the psychological impact of ending treatment for breast cancer. Prior to working in Oncology I too had expected that women would be happy and relieved to have finished their often difficult treatments. However over time I became aware that many women were experiencing difficulties after their treatment, rather than during it, and began to wonder why this was. Finding limited literature in this area, I decided to investigate this further and felt that listening directly to women's narratives of their own experiences would be a good way to do so.

Current Research Aim

The current study aims to better understand the experience of women who have ended their treatment for breast cancer. As such this study is exploratory in nature rather than hypothesis driven. It is hoped that by increasing understanding of women's experiences at this time, provisional suggestions regarding clinical practice and service delivery could be made, and further research encouraged.

It was felt that a qualitative methodology, as outlined in the following chapter, would best meet the aim of the study. Also by employing grounded theory methodology in this study, it was hoped that this study would be more systematic than some other interview studies in the literature to date.

2. METHOD

This chapter outlines the research methodology, procedure and participants for this study. Relevant ethical considerations and issues related to quality in research are also presented.

2.1 Research Methodology

Design

This current study used retrospective qualitative interviews to explore the experiences of women who had ended treatment for breast cancer. The data collection and analysis were conducted according to the methods of Constructivist Grounded Theory (Charmaz, 2006).

Selection of Qualitative Methodology

I chose to adopt a qualitative methodology in this study, as I felt this was the most appropriate way to gain as full an understanding as possible of women's personal experiences. As a novice qualitative researcher, I undertook background reading in different qualitative methodologies to increase my awareness of important issues. I was drawn to what Dallos and Vetere (2005) describe as 'interpretative theme analysis', which is a category of methods incorporating both Interpretative Phenomenological Analysis (Smith, 1996; Smith *et al.*, 1999) and Grounded Theory (Glaser & Strauss, 1967). These two methodologies share common features such as not being initially hypothesis-driven, conducting systematic analysis of qualitative interview data and identifying common themes of participant's experiences (Dallos & Vetere, 2005; Willig, 2001). Despite some key differences between the two methodologies, either would have been appropriate to answer the research question. I decided to employ Grounded Theory in this study.

Grounded Theory

Glaser and Strauss (1967) developed Grounded Theory in response to criticisms regarding the lack of scientific rigour in qualitative research. They proposed a set of

flexible guidelines for collecting and analysing qualitative data, which aim to develop a theory that is 'grounded' in the data. The theory is thought to be grounded as it develops or emerges from the data generated in the research, rather than being based on predetermined hypotheses or theories. Grounded Theory has undergone revisions and modifications over the past forty years, as its original authors have disagreed about how it should best be conducted (Glaser, 1998; Strauss & Corbin, 1990; 1998). Willig (2001) highlights the importance of researchers familiarising themselves with the different versions, in order to select the one which they feel is most appropriate for their research.

Constructivist Grounded Theory

Kathy Charmaz (1990; 1995; 2006) has proposed a modified version of Grounded Theory which allows for consideration of the researcher's role in their qualitative inquiry. The original notion of the 'discovery' of theory, which implies that the theory was already in existence waiting to be uncovered by a neutral researcher, has been criticized for its positivist assumptions (Willig, 2001; Charmaz, 2006). In Constructivist Grounded Theory the researcher is viewed as an active participant rather than a neutral observer, and their influence is acknowledged. Rather than being 'discovered' the theory is said to be generated or 'constructed' by the interaction between the researcher and their participants (Chamberlain, 1999). The research context and personal attributes of the researcher and participants also influence the collaborative generation of a theory. The resultant theory is thus viewed as one potential interpretation rather than an ultimate truth (Willig, 2001). This viewpoint appealed to me, as I share the perception that participants' narratives of experience, and the researcher's construction of these, are only one of a number of possible realities. Furthermore as a novice qualitative researcher, it was somewhat reassuring to choose a methodology where comprehensive guidelines outlining appropriate procedures to follow were available (Chamberlain, 1999). In particular the emphasis on data collection and analysis occurring simultaneously and influencing one another had an inherent appeal to me, as it offers the opportunity to modify and improve ideas as you proceed (Charmaz, 2006).

Preparation for Research Study

A provisional literature review was conducted to gain an increased understanding of the theoretical and clinical research already undertaken about the experience of ending treatment for cancer. Although grounded theory recommends delaying the literature search in order not to influence findings, this is not always practical when constructing research proposals and trying to ensure a unique research contribution (Chamberlain, 1999).

The proposed research topic was discussed with Clinical and Academic supervisors to help refine the research aims and methodology. The researcher then approached numerous members of the Breast Unit to request their advice and support for the research study. These included Breast Care Nurses, Consultant Surgeons, Consultant Oncologists, Radiographers, Database Audit Facilitators and the Caldicott Guardian. After further refinement of the research proposal, it was presented to the Breast Unit team and permission to proceed was granted.

2.2 Ethical Considerations

Whilst developing the research proposal, a high level of care and consideration went in to ensuring that this study would be conducted in an ethical manner. In addition to following guidelines developed by the NHS Research Ethics Committee, I also adhered to the British Psychological Society's (2004, 2006) code of ethics for conducting research in the NHS. The main ethical considerations are detailed below.

Informed Consent

Women who were identified as potential participants were sent a Participant Information Sheet and an invitation to take part by their named Breast Care Nurse (See Appendices 1 & 2). This provided them with clear information about the purpose of the research, their potential involvement and the steps taken to protect them and ensure their confidentiality. Women were invited to contact their Breast Care Nurse or me should they wish to ask any further questions about the study. Women who expressed an interest in taking part were contacted by telephone to arrange a suitable time and place to meet. At this time women were asked to re-read

the participant information sheet and encouraged to ask any questions. I also reminded women of the voluntary nature of their participation, and highlighted their right to withdraw at any time. Once women were happy to proceed with the interview, they completed a Consent Form to document their informed consent to participate in the study (See Appendix 3).

Management of Psychological Impact

Careful consideration was given to the potential psychological impact of participation for the women involved in the study. It was identified that women who had ended treatment for breast cancer might be experiencing adjustment difficulties or increased distress, and that reflecting on these during the interview might lead them to become upset. The Participant Information Sheet contained information about the types of questions the interview would include in order that potential participants felt prepared for this. As I work clinically with people who experience psychological difficulties related to their cancer, it was felt I had suitable training to manage any psychological distress which might arise. It was clearly stated that the interview could be terminated at any time should women become distressed, and all participants were offered the opportunity to be referred to another member of the Clinical Psychology Service to Oncology for additional support should they wish. Time was spent with participants following their interview where they were encouraged to reflect on their experience of taking part and discuss any issues it raised for them. They were also reminded that they could contact their Consultant in the Breast Unit, Breast Care Nurse, GP or myself in the following weeks should any further concerns arise. I wrote to participants' Consultants and GPs to make them aware that they had taken part in the study (see Appendix 4).

Although it was not anticipated that there would be any direct benefit for participants involved in the study, it was hoped that they might value the opportunity to reflect on their experiences and potentially help improve clinical practice for other women with breast cancer.

The psychological impact on me of conducting the research interviews was also considered, and time was made in supervision to reflect on this. In addition, post-interview debriefing was arranged when necessary.

Confidentiality and Data Protection

In order to ensure confidentiality and protect participant's anonymity, any identifiable information (e.g. participant's personal details, consent forms) were stored separately from interview data and could be matched by a numerical code known only to me. All information was securely stored in a locked filing cabinet and on a password-protected computer, accessible only to me and my Clinical Supervisor. Interview transcripts were carefully modified to ensure that all identifiable information was removed. All participant information will be safely destroyed following completion of the research study.

Ethical Approval

Both the Local NHS Research Ethics Committee and the Local Health Board Research and Development Department granted approval for the research study to proceed (See Appendices 5 & 6).

2.3 Participants

Recruitment of Potential Participants

I was granted permission to access the Breast Cancer Patient Database by the Caldicott Guardian for the Breast Unit. A meeting was arranged with the Audit Facilitator in SCAN (Scottish Cancer Audit Network), who manages the database and provides access for approved research. A database search was conducted to identify women who met the inclusion criteria, which had been developed in collaboration with staff from the Breast Unit.

The inclusion criteria for this study were:

- Women with a diagnosis of breast cancer

- Women who were node-negative and metastases-free on their staging results at diagnosis
- Women with a good to moderate prognosis at diagnosis (as rated on the Nottingham Prognostic Indicator; Galea *et al.*, 1992)
- Women who had had surgery, chemotherapy and radiotherapy as their treatment for breast cancer (and were still taking hormone-therapy medication)
- Women who were HER2 negative (and thus were not being treated with Herceptin)
- Women who had ended their main treatment two to six months previously

Women with no known disease spread at diagnosis and a good to moderate prognosis were selected as it was felt likely they would successfully complete their treatment. It was decided to include women who had undergone all three main active treatments (surgery, chemotherapy and radiotherapy) as each treatment might impact differently on how women experience the end of treatment. As the vast majority of women treated at the Breast Unit are prescribed hormone-therapy treatment it was felt important to consider whether this had an impact on how women perceived ending active treatment. It was specified that women be HER2 negative because women who are HER2 positive still have regular ongoing contact with the Breast Unit to receive Herceptin treatment for a year, and thus have not ended their more active treatment. The timeframe of between two and six months post-treatment was decided upon in reference to the relevant literature and to allow enough time after treatment not to be intrusive to women, but not so long they forgot the details of their experience.

A list of 24 potential participants was generated by searching the database for women who met the inclusion criteria for this study. Information about each woman was added to the SCAN database at the time of their diagnosis, and it was therefore possible that their situation had changed since this time. As such it was important to discuss all potential participants with their named Breast Care Nurse to assess their suitability, prior to inviting them to participate. Women were excluded from the study if they had a significant disability unrelated to their cancer, had experienced

significant delays in their treatment regime or were thought to be too physically unwell to participate. 18 women were identified as suitable potential participants and were invited to participate by their Breast Care Nurse. Women were asked to contact me if they were interested in participating in, or hearing more about, the study.

Research Participants

Nine women, aged between 46 and 66, contacted me to volunteer to take part in the research study. An interview slot was arranged at a time and location (either their home or the Cancer Centre) that was suitable for the participants. I interviewed eight of the women individually, with the other woman requesting that her husband be present during her interview. Interviews lasted between 35 and 92 minutes, and were recorded using a Digital Voice Recorder.

All the women had received treatment for breast cancer at the local Breast Unit; they all underwent surgery and chemotherapy, and were recommended radiotherapy. Eight of the women chose to have radiotherapy and had finished their treatments between two and six months prior to being interviewed. The other woman was interviewed nine months after finishing her treatment because I was unaware she had opted out of radiotherapy. All nine women were taking hormone medication at the time of their interview. Five women were married, two were divorced, one was single and one woman was recently widowed. Eight of the women had children, with half of them having children who still lived at home with them. Eight of the women were employed; two had continued to work throughout their treatment, five had returned to work following the end of their treatment and one woman was keen to return once she was physically well enough. The other woman had retired before she was diagnosed with breast cancer.

The majority of the women reported not having experienced any major physical or mental health problems prior to their diagnosis of breast cancer. However, one woman had a history of anxiety and was taking medication at the time of interview, and another woman had been successfully treated for ovarian cancer in the past. None of the women had previously attended the Clinical Psychology Service to

Oncology, and none felt they needed to be referred following their interview. Participant information has not been presented individually in order to protect confidentiality.

2.4 Research Procedure

The following section will outline the methodological steps undertaken in collecting and analysing data, referring to the literature base and refining further data collection. It is important to note that these processes do not occur in a linear fashion, and are in fact interconnected and occur simultaneously (Chamberlain, 1999).

Data Collection (Research Interviews)

In preparation for conducting the research interviews, I spent time considering pertinent issues involved in carrying out qualitative interviews. Participants' accounts of their experience are known to be influenced by the relationship they form with the researcher, which in turn depends upon the way the researcher behaves and asks their questions (Clandinin & Connelly, 1998; Holstein & Gubrium, 2004). As such it is essential for the researcher to establish rapport with their participants, as this impacts on the level of shared understanding they can achieve (Fontana & Frey, 1998). Given that forming collaborative relationships is part of my clinical role with women with breast cancer, it was hoped that this would be a good starting point for carrying out qualitative interviews. In fact Dallos and Smith (2008) highlight that core therapeutic skills, including empathy, listening and interpretation are key in conducting research interviews. However, it is also necessary to be aware of the distinctions between clinical and research interviews. Through discussion with supervisors and peers undertaking qualitative research, it was agreed that research interviews should be more relaxed and informal than a clinical interview. As the aim of research interviews was deemed to be increased understanding, it was felt important to follow the participants' narrative and agenda, rather than imposing my own structure. Phrasing questions in an open and neutral manner was identified as being integral to this and was therefore practiced with peers to increase my confidence in interviewing in this way.

Prior to commencing each interview I emphasized to participants that there were no right or wrong answers to any of my questions, and that my main aim was to hear about their own personal experience. The interviews started by asking participants about their breast cancer treatment, as it was felt important for them to set the scene and relax in to the interview. Following this participants were asked about their experience of ending treatment, and I then asked follow-up questions based on their responses. An interview guide had been devised in advance, and included very broad open-ended questions about key areas of interest (See Appendix 7). Although the emphasis in initial grounded theory interviews is on being very non-directive and following the participant's lead, Charmaz (2006) identifies that a guide can be beneficial in increasing novice researchers' confidence and freeing them to listen closely to participants' narratives. However I noted that once the interviews commenced I rarely referred to the guide as I became immersed in the participants' stories. This helped create a relaxed and open setting which helped the interaction to feel less like an interview and more like a 'directed conversation' as recommended by Lofland and Lofland (1983).

As data collection proceeded, I was also engaged in analysing early data and referring to relevant literature, which helped to identify preliminary themes for exploration. These themes were then brought in to subsequent interviews which allowed participants to elaborate further on these ideas if they felt they were of relevance (Charmaz, 1995).

Data Management

All research interviews were recorded on a Digital Voice Recorder and then voice files downloaded on to a password-protected computer. I then transcribed the interviews verbatim, adding in any non-verbal communications that helped provide context to the participants' verbal accounts. This process helped to immerse me fully in the data and increase my familiarity with the participants' accounts. Following completion of the transcript, the interview was listened to again whilst reviewing the text to check the accuracy of the transcript and ensure that all identifiable

information had been removed. Transcripts were then imported into qualitative data analysis software NVivo 7 (QSR, 2007).

Data Analysis

The main analytic task in grounded theory is coding, the process by which raw data are labelled and interpreted. Initial coding involves examining the transcript thoroughly, and allocating descriptive labels (or 'codes') to the events or actions occurring in the data. It is important to do this line-by-line, or for each unit of meaning, in order to help the researcher think about the material in systematic ways (Thomas, 1993). This also prevents researchers from importing previous theories or preconceptions (Charmaz, 2006). It is important for researchers to record all potential meanings that occur throughout the process, so it is possible for each line of transcript to have more than one code.

This initial coding was undertaken using NVivo software which facilitates the storing and organisation of codes. I highlighted each relevant section of transcript and assigned it one or more codes (or 'nodes' in NVivo terminology). Following the initial coding of the first two interviews, the coded transcripts were shown to the research supervisors (See Appendix 8 for an example section of coded transcript). This was to ensure that my coding made sense in the context of the initial data, and to allow the opportunity for new codes to be suggested which had not occurred to me (Barry et al., 1999).

During the initial coding process I found it helpful to ask myself questions about the data I was working with, and to record any ideas or interests identified in the data (Charmaz, 1990). These emerging ideas and initial codes were then incorporated into subsequent interviews, through additional questions, in order that they could be elaborated on or discarded by the participants depending on their relevance (Charmaz, 1995).

As further data were collected and coding continued, comparisons were made between the codes and the sections of transcript they were based on. This constant

comparative method is integral to Grounded Theory research and allowed me to start to conceptualise potential categories of data. Similar codes were clustered together and then, by looking for similarities and differences between instances and participants, the most pertinent codes became more apparent and categories started to emerge. At this stage coding moved to a more focused and analytic level, and further literature was accessed in order to try and understand possible ways to interpret emerging ideas. Integrating new literature at this later stage in the research process was a useful strategy that prompted me to explore alternative ways of analysing the data. Continued questioning was also important in helping me decide which codes were of most significance and should be raised to being potential conceptual categories (Charmaz, 1990; Chamberlain, 1999).

Throughout the coding process, I wrote memos and developed diagrams to help in the process of developing or constructing a theory of the data (Chamberlain, 1999). Writing memos was important for engaging with my interpretation of the data and examining the properties of and relationships between provisional categories (Pidgeon & Henwood, 1996). Developing diagrams was beneficial in providing visual representations of the analysis and keeping track of my thoughts and ideas as categories were merged with one another or broken down over time (See Appendix 9 for an example early diagram). Regular meetings with my supervisors throughout this process helped to refine my thoughts and explanations about the structure of potential categories.

In the later stages of the data analysis, the interview transcripts were reviewed and sections recoded as I became more attuned to categories. In turn the categories, and sub-categories, became more refined and potential relationships between them were explored through the use of memos and diagrams. Creating tree nodes ('categories') in NVivo helped me to organise the initial free nodes ('codes').

Sampling

The concept of theoretical sampling aims to generate further data that will explain any gaps in the theoretical categories (i.e. analytically-driven data collection). Strauss

& Corbin (1998) recommend that this is best done by purposefully selecting participants whose experiences will potentially contradict or add to the emerging theory. They acknowledge that this is not always practicably possible and that modifying interview questions as data collection progresses is an alternative. It was not possible for the current study to undertake true theoretical sampling given the recruitment procedure and the limited information I had about potential participants.

In traditional grounded theory it is advised that data collection and analysis continue until theoretical saturation is reached. This is said to be a point at which no new theoretical concepts arise and all data can be accounted for by the grounded theory. In the present study time constraints restricted the collection of further data, and so theoretical saturation was not reached. However there have been some debates in the literature regarding how realistic or achievable the concept of saturation actually is (Dey, 1999; Willig, 2001) and less emphasis is placed upon it in constructivist grounded theory (Charmaz, 2006). In fact Brocki & Wearden (2006) emphasise that there is always the possibility that confounding evidence could be uncovered in the next interview. It is also important to remember that qualitative researchers aim not to present generalisable findings, but rather to try and reflect the diversity of experience in the chosen population (Harding & Gantley, 1998).

Writing the Draft

Charmaz (2006) emphasises that writing and rewriting drafts of the theory that has been constructed is an important stage in the analysis. I continued to generate thoughts and ideas about the theoretical categorization during the process of writing up the research results, which led to further consideration and refinement.

2.5 Reflective Practice

I kept a reflective research journal throughout the study in order to record my thoughts, feelings and decisions about the process of undertaking this research. This was beneficial in monitoring my practice and development of skills in conducting qualitative research, increasing my awareness and understanding of potential biases

or influences I might have on the process and results, and also keeping an audit trail of my theory construction (Burck, 2005). For further discussion see Personal Reflection chapter.

2.6 Quality in Qualitative Research

It has been argued in the literature that qualitative research should be judged according to relevant criteria, rather than those associated with quality in positivist research (for example, reliability and generalisability). A number of checklists have been devised which have been useful in demonstrating the thoroughness and quality of qualitative research (Popay, Williams and Rogers, 1998; Stiles, 1993). Although different terminology has been used, there appears to be some agreement that a key component of good qualitative research is 'trustworthiness' (Lincoln & Guba, 1985; Schwandt, 1997). The four aspects of trustworthiness will now be outlined, along with the steps I have undertaken to attempt to meet them.

Credibility

Charmaz (2006) described the credibility of qualitative research as the extent to which the findings are thought to accurately reflect the views of the participants. Direct quotations from participant's narratives have been included in the results in an attempt to demonstrate that the categories represent the data which was collected. A number of member checks (or respondent validity) have been undertaken to ensure the credibility of the research findings. Firstly participants who wished to do so were sent a summary of the main themes from the interview and invited to respond should they feel these were misrepresented, which none of them did. Also important themes from each interview were incorporated into subsequent interviews to check their suitability with other respondents (Elliot, Fischer & Rennie, 1999).

Triangulation, the process of seeking information via more than one method or source, is another useful strategy for ensuring the credibility of qualitative findings (Dallos & Vetere, 2005). Although only one method of data collection was conducted (interviews) by one researcher, the study did involve the use of investigator triangulation (Jamieson et al., 2007) where my interpretations of the data

were discussed with research supervisors. In addition, I asked clinicians experienced in Psycho-Oncology to outline the factors they felt were important at the end of treatment, which coincided with many of the categories generated in this study.

Transferability

Transferability refers to whether it might be appropriate to apply the current findings to other contexts. To identify the extent to which the reader could transfer these findings, I have been transparent about the current research setting and provided descriptive information about the participants. In addition I have provided rich enough data in the results to allow the reader to identify whether the findings have relevance in their own setting (Lincoln & Guba, 1985).

Dependability

This criterion refers to the reliability of the findings and whether they would be replicated if the same research study were undertaken again (Erlandson et al., 1993). I have developed a clear audit trail throughout the undertaking of the research in order to keep track of the process of analysis and to allow for inspection, as demonstrated in this write-up (Rodgers & Cowles, 1993).

Confirmability

The final aspect of trustworthiness is concerned with assuring the findings are objective and not unnecessarily influenced by my own preconceptions or biases. This is not as relevant in Constructivist Grounded Theory, where the collaborative role of both the researcher and participant is encouraged in theory generation (Charmaz, 2006). However it was important for me to record in my reflective diary any preconceived ideas and how they might influence the process.

2.7 Dissemination of Research Findings

A summary of the research findings will be sent, as requested, to all the participants. I have also arranged to present the findings of the research to the whole team at the participating Breast Unit, and to Clinical Psychology colleagues working in an Oncology setting.

3. FINDINGS: CONSTRUCTING A NEW NORMAL

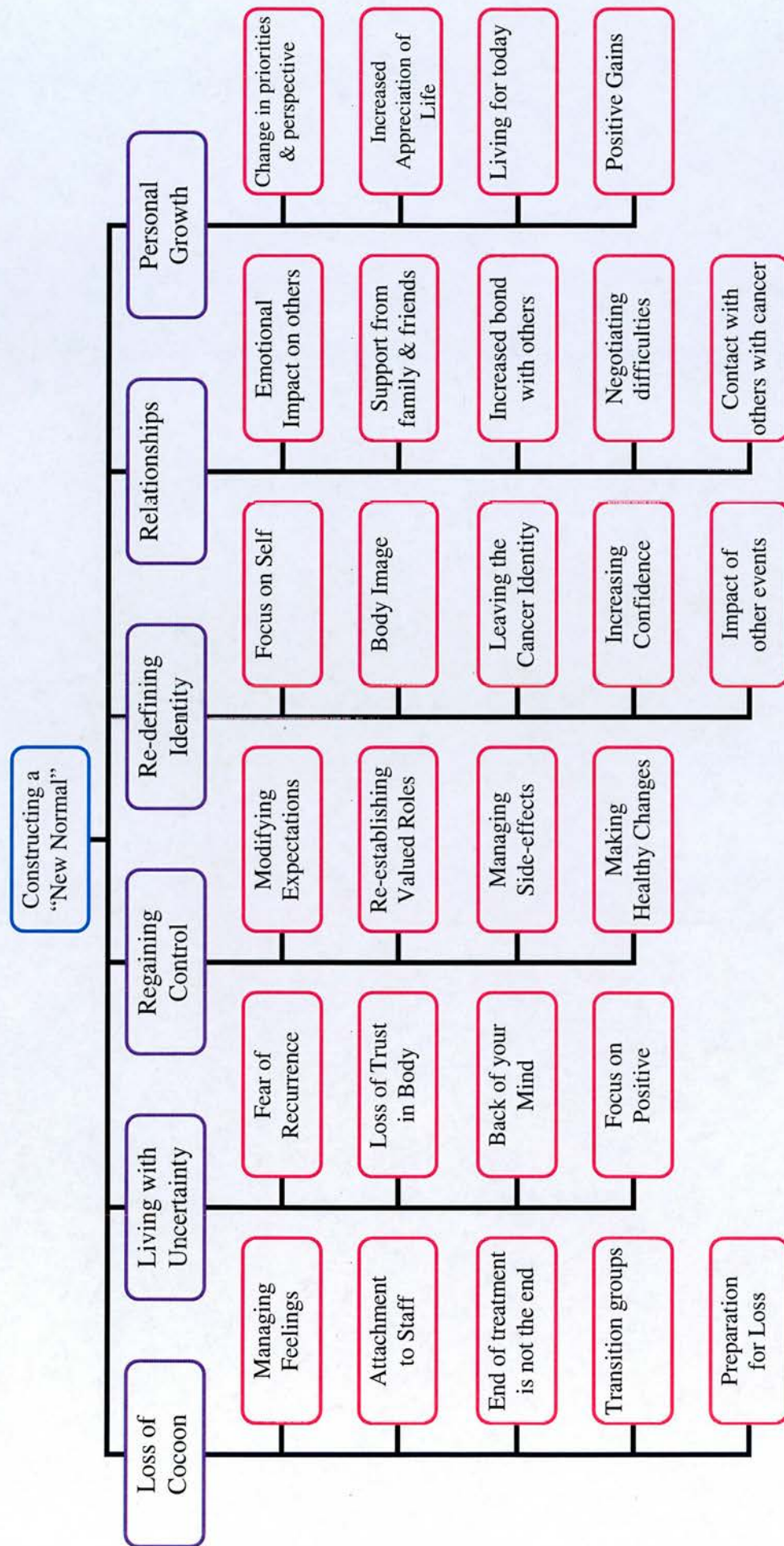
The core category that emerged from this grounded theory was that women's experience of ending treatment for breast cancer involved them having to construct a "new normal" life. Although women often looked forward to getting back to normal after their treatment ended, on the whole it was acknowledged that this was not possible. Women were inevitably changed by their experience of breast cancer, and its impact affected a variety of domains of their lives and of those around them. There was also a sense of the world moving on and changing around these women, whilst their lives were put on hold for the duration of their treatment in the cancer world. This meant it was not possible for women to slip back into normal life at the same point they left it, because they were not the same and neither was 'normality'. In addition to the changes that happened outwith women's control, women's experience of breast cancer also provided them with an opportunity to review their lives, evaluate what was important to them and think about changes they might like to make to their future.

There were six main categories that combined to build up the picture of constructing a "new normal"; loss of cocoon, living with uncertainty, regaining control, redefining identity, relationships and personal growth (see Figure 5). Each of these categories, and the subcategories which comprise them, will be outlined in turn. The findings of the analysis will be presented in this section and then discussed in the subsequent discussion chapter.

Quotations from the interview transcripts will be presented to illustrate each subcategory. Within these quotations, ellipsis points indicate pauses in speech, brackets enclose non-verbal aspects such as laughter, and square brackets include changes made to preserve anonymity.

Please note that all participant names have been changed in order to protect confidentiality.

Figure 5: Diagrammatic Representation of Constructing a New Normal



3.1 Loss of Cocoon

The women described a sense of loss as they moved out from the cocoon which encapsulated their treatment in the Breast Unit. The experience of this loss included needing to manage their feelings associated with ending treatment, coping with the change in their attachment with staff, the realisation that the end of treatment was not the end, participating in 'transition' groups and reflecting on the lack of preparation for this loss.

Managing Feelings

Women described experiencing a wide range of emotions at the end of their treatment and in the subsequent days and weeks. Often women expected to feel excited or relieved, and many did initially, but this sense was often short-lived. Afterwards women were faced with unexpectedly feeling deflated, low in mood, tearful, and disappointed. Some women described feeling quite alone and vulnerable at this time, and needing some time to themselves to come to terms with how they were feeling.

Yeah quite excited, but I think having the last treatment and still having the side effects ongoing from that. I think that, I think my mood dropped a wee bit I think at the end of it... It was quite a mixture of emotions, excited, maybe a bit of an anti-climax... I felt quite down, quite tearful at times. Em, and yeah, quite scared about going forward and doing things on your own after attending hospital for so long. (Carol)

So you know, you accept everything there is with the chemotherapy, you know it's going to be horrible, you get used to the cycles... And I hadn't anticipated this bit afterwards. And I found myself getting weepy about things, you know I would sit and watch, remember there was the big floods? And I would sit and watch all the people in the floods, with the tears tripping down my cheeks because people, you know, were in a bad state (*laughs*). You know, it was, it was like, it was very similar to when you've just had a baby, it was that kind of emotion. You know it was like a hormonal reaction, to it. (Barbara)

Other women recalled being more focused on the relief of no longer needing to endure the treatments, and were happy when they first ended their treatment.

And eh, I went and said it's my last one. I went 'hallelujah', I said 'I'll be skipping out... the ward, laughing'... I did I felt thank God that's over. But it was like when my chemotherapy was finished as well, I said 'right that's me'. And the nurses said 'oh its really nice that somebody's actually smiling going out of there'. And I thought, thank god that's over. (Anne)

Attachment to Staff

Women reported that staff at the Breast Unit provided them with a range of support during their treatment; advice and guidance when overwhelmed at diagnosis, medical expertise to treat their cancer and manage side-effects and also reassurance about their worries and concerns. In addition the majority of women reported the benefits of forming positive personal relationships, where they felt treated as an individual not just another patient. When women were thrust quickly in to the 'cancer world' after diagnosis the staff immediately become an important part of their daily lives. At the end of treatment these important relationships abruptly came to an end for women. They became more aware of the divide between health professionals and themselves as a patient, in that they could not keep the same level of contact and had not become friends. This could be difficult for some women to cope with if they had formed an attachment to staff, as they felt abandoned at a time of need.

But I can remember we had such a laugh that day, and again, you know, having to say goodbye to them was extremely difficult. And it sounds ludicrous cause its, its horrible treatment. But nevertheless, you form such lovely relationships. And I don't think I'd thought about the fact that there would suddenly be nothing. But there was suddenly nothing... (Barbara)

Other women felt that they had no right to continue relationships with their Breast Care Nurse, although provided with information to the contrary, as they felt other women were more in need of the service than them.

But then, no, at the end of the day when you think of it.... When I was first diagnosed she was there, and I keep thinking to myself, you know, what if all these people she'd seen previously had finished their treatment and blah blah. What if they kept phoning her?... and I'm just starting my treatment and I couldn't get through. And if I couldn't get her help because all these people who've already had their treatment and are ok but... And that's the way I thought about it, and I thought well, there's people that are just being diagnosed, or half way through their treatment, need her help more than I need it. If that makes sense, you know? And I thought well, at the end of the day, I've got to get on with my life and I've got to do it myself. (Diane)

As transition back to community care was encouraged after treatment finished, women's relationships with their GP became important at this time.

End of treatment is not the end

Women described the realisation that just because their active treatment had ended did not mean that their cancer experience was over. It was often at this time that

women began to experience the psychological impact of what they had been through, and took time to stop and reflect on everything that had happened. Some women felt unsure what to do with themselves at this time, after having based their daily routine around attending treatment at the Breast Unit. They described ending treatment as an important stage in their recovery or cancer 'journey' but had realised it was not the last stage.

You miss it, you do miss it. Not the treatment but just I suppose having that in your day, eh? And then it's left to you... which way you go really isn't it? I mean they always say that everybody's different but you know. I'm trying to think what track I'm going along. Eh... I think really it's just how you cope with life yourself... It's just actually working your way through as best you can... (Grace)

I don't know, you feel a bit flat. I think, sort of for all that time you've got, you know you've got appointments to come to and you know things are being done about it and everything that's being done is being done, you know that can possibly help. And then all of a sudden it just sort of stops... And you're left sort of high and dry. Em... not that I ever felt I couldn't contact anybody, you know, or anything like that because I'm sure, you know I know I could have phoned up any of the breast nurses or anything, but you just feel that, what should I be doing now? Sort of thing. (laughs) (Helen)

'Transition' Groups

A number of the women had attended the End of Treatment group and/or the Exercise group at the Breast Unit, which are held specifically for women who have finished their treatment. It would seem that these groups provided a valuable function for women in the sense of providing a transition between the cancer world and their own lives. The End of Treatment Group allowed women to share their common experiences and understanding, which reminded them they were not alone, and they got advice from staff and other women. The Exercise group helped not only to increase fitness and confidence, and reduce fatigue, but also provided a supportive environment where cancer was not the primary focus. The women said they would recommend these groups to other women, but also suggested that having individual end of treatment meetings with breast care nurses might be helpful for those who felt unsure in group settings.

And I'm very glad I went. And I think that helped, because instead of it being 'there's your treatment, treatment's finished, that's it, that's your cut-off point, come back in a year's time'. Instead of that then we had that continuation... and then, so it's a gradual drop off rather than a cut off. So I think that helps more than anything else. Cause you've had everybody running around, looking after you, blah blah blah.

And I was so glad to get finished the treatment and I really just wanted them to leave me alone, but at the same time I still needed something, and that was it. I think that was great. (Diane)

I think for some people, for some people they need to get to the end of their treatment and they have to say that's it over and done with and need to walk away from it. For other people I think they, they probably need an ongoing support. And I think I fit somewhere in the middle of the two of them, and I think once I'd been to that meeting I felt happier because I knew that if I had any queries that I could, em, I could just phone. (Barbara)

Preparation for Loss

The majority of the women could not recall having particularly thought about or discussed the end of treatment in advance, or having considered the potential feelings of loss. Most women described thinking in the very short term when they were undergoing their treatment, and just having concentrated on facing each day at a time and managing the treatment. As such they tended not to think ahead, other than look to forward to life getting back to what it was before cancer. The idea of life going back to normal was the light at the end of the tunnel that kept them going through treatment, so they did not want to hear that it might not happen. Other women recalled that although staff had warned them that the end of treatment could be difficult, they had not thought it would apply to them, especially if they had coped well through treatment.

I really feel that, you know as I say I like to know the worse that can happen... So, you know and also what can happen after the treatment and that you won't feel better immediately after the treatment stops. Em... that things can get a bit worse before they get better, that sort of thing. I mean the only thing is I would have found it easier to cope with knowing this, you know, could be bad and could take much longer than I thought. My GP was telling me it can take months and months to get back to normal. So I mean that was quite depressing when I first heard that. (Helen)

There was a sense that it might have been beneficial for women, and normalised their experiences, to have been better prepared by staff about what difficulties they might encounter after treatment. It was, however, also identified that having this information in advance might have led women to encounter difficulties because they had expected them.

And you read the literature and it doesn't warn you, cause they don't want it to be a self-fulfilling prophecy. But... I think I would maybe say to people to think about having something in place. I think you have to be really careful because you do not want to suggest to anybody at any time that you might have a negative response. Em,

but I don't know that I was really prepared for that, for that bit. And I'm sure things must have been said to me at some point but somewhere along the line, I don't know that I had taken it on board. (Barbara)

3.2 Living with Uncertainty

Another task women faced in constructing a new normal was learning to find ways to live with the uncertainty they experienced after ending their treatment. This incorporated both a fear of recurrence and a loss of trust in their body, which women tried to handle by putting it to the backs of their minds and focusing on the positive.

Fear of recurrence

Most women noticed a marked increase in their fear of cancer recurrence following the end of their active treatment. They expressed fears that perhaps the treatment was only keeping the cancer at bay, and it would return once the treatment stopped. Attending treatment was acknowledged to be an active coping strategy which made them feel they were doing something to fight their cancer, and now it felt like they were doing nothing (despite all taking hormone medication). The fear of recurrence was not only motivated by a fear of death, but also by the fear of having to endure the treatment again now that they knew what that would entail.

So I think it was just getting to feeling a bit normal again. Cause you still feel... and I think in my mind, I kept on thinking, if I was getting my appendix out, you go in, have your appendix out, your operation's over, you have a recovery and that's it. But it's a different kind of way you think, because its cancer... for some unknown reason. I don't, I can't quite think how I, how I feel that way. I've spoken to another few girls that feel the same way, you know, it's kind of a strange thing, the cancer thing. I think it's just in case there's a recurrence really. But I know that I can't keep on thinking like that cause I've got my life to, my life, to lead. (Anne)

The information that women had received about their cancer status and prognosis impacted upon the extent to which they worried about fear of recurrence, although it was acknowledged that not even the doctors can be certain. Women also expressed awareness that their fears of recurrence were perhaps further exaggerated by having met women with secondary cancer in the Breast Unit. Some of the women chose not to contemplate the possibility of recurrence.

I suppose the whole thing is you know like one of the first consultants that I saw had said you know you can never say that you are free of cancer. Like once you've had

the diagnosis then, em, it's something that will always be around for you. And basically I don't agree with that. You know as far as I'm concerned I've actually gone through my treatment and as far as cancer's concerned I drawn a line under that. You know it's passed. And I've had everything that they can possibly throw at me thrown at me to ensure that it won't come back and I don't know whether it ever will or it won't. But I'm certainly not going to spend my life worrying about, you know, what if it does. I really don't at this point have any concerns about that at all. (Fiona)

Loss of Trust in Body

Women also experienced a sense of distrust about their body, which exacerbated fears of recurrence and uncertainty. As the majority of women had felt physically well when they were diagnosed, there was a sense that their body had betrayed them by hiding the cancer without them knowing. After treatment women had to cope with a number of physical changes in their bodies, including breast pain, swelling and scar tissue, and they had to try and decipher whether these were normal and trust they meant nothing sinister. Women reported that the smallest aches and pains were perceived as a potential threat, which led them to get stuck in the “cancer mindset”, and they became hypervigilant for any unexplained changes or sensations. They lost confidence in their own judgement about what was normal.

I'd started to get paranoid about things as well. Em, when I was feeling myself I could feel lumps and bumps everywhere. And what I was feeling was my rib cage and I knew it was my rib cage.... I thought they were lumps and I went to see my doctor. And I said I'm sorry I'm here with an outrageous outburst of paranoia (*laughs*), and she said no that's fine. But I think you lose confidence. I think you lose confidence in your own body. And I think the scary thing about something like breast cancer is, you know, I felt a well healthy person. I was relatively fit for my age, you know I did a moderate amount of sport, I worked incredibly hard. I felt like a very very healthy person. So there is always a niggling doubt in your mind, that that thing has been in your body and multiplying and growing, and you had no idea. (Barbara)

Back of your Mind

Women identified that they could have easily become overwhelmed by thoughts of recurrence and their own mortality, if they did not do anything about them. As such, women made an active choice to try not to become consumed by fear, and instead to cope by putting the thoughts to the backs of their minds.

So I mean I cannae... you know, I don't know, you don't put it completely out your mind but I think you've got to put it somewhere, you know what I mean, there's no way I would ever be dwelling on this. I mean it's happened, I've been a victim of it,

it's happened to me, ok hopefully I'm ok and I will be for lots of years, who knows, but in the meantime you have got to just get on with your life. (Emma)

For some women it also seemed as though they had coped with the difficulties of treatment and what they had been through by also pushing memories out of awareness.

And then just put everything that's happened to you behind you, really.... you know, don't think about what your first day was like when you had your chemotherapy, or what it was like when you had your radiotherapy, put that back in your mind. Cause I think you could be tortured with a lot of stuff like that. you know if you kept on sort of thinking... just put it to the back of your mind. And just its time to move on really. (Anne)

Women were unable to banish fears of recurrence from their awareness completely, as they could not reassure themselves that their concerns were irrational or incorrect. It would seem that for most women, as time passed from ending treatment, their fears of recurrence would gradually reduce and it would be easier for women to put them to the back of their minds. However the fears could be instantly triggered again by reminders of their cancer experience like television adverts, viewing their mastectomy scars or experiencing unusual pains. One woman reported a flashback of her treatment which triggered the physical sensations she experienced during chemotherapy.

There has been a lot of change, yes.... Certainly, thinking back to how I felt when I finished treatment, I know that I think your mind blocks out an awful lot of things and there's an awful lot I actually can't remember until you have to sit down and make yourself think about it. I guess it's kind of buried away somewhere in my mind. Then watching Casualty for example, a couple of weeks ago there was somebody on an IV infusion and the alarm went off and I actually felt physically sick, the hairs went up on the back of my head. It was exactly the same alarms that they have on the drip counters across on [the chemotherapy ward] so I could smell the chemo and taste it. And that's the first time I've had any kind of major flashbacks to it I think... (Carol)

Focus on Positive

In addition to having avoided negative cancer thoughts, women also mentioned having managed their uncertainty and fear of recurrence by focusing on the positives in their situation. They relayed their gratitude for the good treatment and care they had received in the Breast Unit, and the fact that they felt fortunate their cancer had been identified in the first place. The majority of women also noted that they felt

having a positive attitude and being optimistic about their futures was helpful in their adjustment.

You know I felt good and I just really got on with it and people were saying actually, you know you're amazing, you're positive. But you've got to. I think it is part of the healing process. You've got to be very positive, you know. (Isla)

Some of the women acknowledged that their outlook and how they viewed their situation might appear unrealistic or naive to others, but that it was the best way for them to cope.

Em, my mother had breast cancer so when I was diagnosed... that is frightening because I had seen what it could do to somebody. However you have to appreciate it is not necessarily the same cancer I have, and I find that what I had to do was latch on to all the positive things. I was very circumspect about what I read, I was very circumspect in conversations. And if a conversation started to take a line that I couldn't cope with, I just stopped the conversation. And it might be seen as slightly burying your head in the sand, but I found that being positive was what gave me the strength to keep going. (Barbara)

Women also drew comparisons between themselves and other people who were worse off than them, which enabled the women to reduce their own anxieties and focus on the positive. In addition, thinking about what they were planning for the future and the positive aspects to their non-cancer lives helped women to stay strong.

Well for a start I just thought I'm too young for anything to happen to me (*laughs*). Too young, 58, em... well I think you've got to think of your family and what you want to, you know what your goals are still. I've still got loads of things I want to do and when I retire, you know, doing, again "me time" and my husband's retired so I mean we're going to cover good time in [holiday home]. I've got a wee house abroad so... you know we are going to do that and spend lots of time with my granddaughter and my son. My family's very important to me. So I would say that's what kept me going. I just thought I'm going to, there's no way I'm going to lie down to this and I never, I never. (Emma)

3.3 Regaining Control

Women described regaining some control in their lives as an important step in helping them to adjust and establish their "new normal" lives. This was achieved through modifying expectations, re-establishing valued roles, managing side-effects and making healthy changes.

Modifying expectations

All the women mentioned needing to alter the expectations they had of themselves after ending treatment. As outlined above most of the women had high hopes that they would feel much better after ending treatment and be able to do everything they could prior to their cancer experience. In order to cope with their disappointment and frustration when this was not the case, women needed to change their goals and expectations of themselves, to make them more realistic for how they felt at the time.

You set goals for yourself that you would like to do... but then the reality of it kinda hits you, you can't actually achieve them at the pace you want to because you're just, I felt so tired afterwards I think. I had less energy than I had anticipated I would at the end of it. And I think, through all the treatment I felt it was OK to go and have a lie down in the afternoon and things, but afterwards you kinda think ok I still have to go and have a lie down in the afternoon, but you know don't feel quite so good about it. I've got over that now, I think you kind of, you learn to pace yourself then, you don't feel quite so bad about it, don't feel so guilty... (Carol)

It's when you are in this stage of recovery where you're saying right I can do more, like mentally you think I can get on and do such and such or whatever, but physically I can't actually do that. So it's quite frustrating and anxiety provoking. But I know that I will be back. (Fiona)

Women also mentioned the marked impact that other people's expectations could have on them at this time. There was a sense that some people in the women's lives forgot what they had been through once the treatment was finished, and felt they should be able to manage more than they could, which left women feeling even worse about their reduced capabilities. Some women were able to then modify other people's expectations, to encourage them to be more realistic, which helped them to feel less criticised and more in control.

Still feel quite tired. It's not all the time, it's just now and again and sometimes I feel, em, other people forget as well, you know that you've had such a hard time and eh... sometimes I feel, you know, some people are just asking a wee bit too much. But what can you do, eh? (Grace)

Other women reported that they sometimes felt frustrated by people having too low expectations of them, and overprotecting them or treating them as if they could not manage anything.

I was really pleased to finish my treatment, just trying to get back to normal. The only thing is, my husband won't let me get back to normal. He keeps 'don't do this, don't do that, don't do the next thing'. That's all very well, but I know me, I know my body and I know what I'm capable of. And if I'm not able to do something then I won't do it. So it's other people round about you are so annoying. Family, pain in the neck (*laughs*), they really are. (Diane)

Re-establishing Valued Roles

Women reported that other people often helped them during their treatment by taking over roles and tasks for them when they could not manage, especially in the home. Although this was very beneficial, it could also sometimes have the effect of making women feel they were not needed or valued. As such, re-establishing aspects of important roles in their lives, whether as mother, employee or wife, was an important aspect of regaining control after treatment ended.

So mum, in particular, was there an awful lot through things and I think now is still tending to fuss and do things that she was doing when I really was unwell at the time. And now I think back off (*laughs*) I can do this now, I'm not ill, you know, just let me do things my own way now. (Carol)

Even if women were unable to manage everything they used to, it was important to feel as though they were part of decisions and tasks and could have some choice. Also some women reported being happy not to have to resume full responsibility for all their prior roles, and that they had negotiated new routines and ways of working at home.

My husband's had to change his life like, you know he's had to learn to do all the cooking and all the ironing and things (*laughs*)... It's changed what I do. I am getting better and I just pray each night that each day I'll get that bit stronger and this last week with the weather being nice we've sort of been out in the garden. Not that I've done very much but at least I've been out trying to get it organised a bit you know. And as I say my husband, he's done all the cooking, like I go shopping and tell him what we'll have and things, you know. I put the washing on and he hangs it out and then he does the ironing. But he keeps saying I think she's maybe just swinging the lead a bit (*laughs*) and should be getting on with things. (Isla)

Returning to work was an important stage for many women in re-establishing valued roles, and was a marker that they were improving and establishing a sense of normality. It did seem that women were apprehensive about whether they could still manage their role, given the length of time they had been out of the routine. Most women had gradually re-integrated to their work at the time of the interview, and felt they had a better work-life balance than prior to their cancer as work was now less important to them.

I just dinnae have the commitment that I had before I was ill. I just dinnae have the same thingmay, I mean I do my job and all the rest of it... But it's not so important now, you know? It's only a means to an end, to get money at the end of the month, you know, that's it. (Grace)

One woman had been unable to return to work due to physical side-effects, and found it very hard not to have that valued role in her life.

I'm very aware of the fact that I couldn't do nine-tenths of the job at the moment. And that... that as I say probably bothers me more than actually going through the treatment itself. (Fiona)

Managing Side-Effects

All the women explained that they continued to experience ongoing side-effects following their treatment. Fatigue was the most common and frustrating side-effect for women, which was often perpetuated by disrupted and reduced sleep. Women also mentioned problems with pain and aching limbs, and menopausal symptoms, in particular hot flushes and night sweats, which they attributed to their hormone treatments.

Some other people I think they think 'oh good she's five, six months down the line now, everything's back to normal'. I think they forget you are still feeling tired and very, well not back to your normal self yet. Some people I think, forget quickly. You're over your treatment, you're finished, everything's fine. Em, if you say 'I'm really tired today' they say 'oh why is that?' (*laughs*). But, yeah, it's... people understand different things in different ways. (Carol)

A couple of women had experienced more marked physical side-effects, which they had felt unprepared for by the doctors. One woman had experienced marked peripheral neuropathy and another had life-threatening blood clots after her chemotherapy and spent three weeks in intensive care. Women often commented on the fact that their treatment for cancer had made them feel worse than they had before the cancer was discovered, and that the treatment itself caused further health problems. In addition the combination of different side-effects meant it was hard for women to know what to do to overcome the impact of side-effects and regain control over their bodies.

The difficulty is, you know I was reading all about fatigue and I am still really tired but you know, the best way of sort of helping that is to get out, get fresh air, get a good walk and my heels being the way that they are, I do as much as I can do but it is very painful. My feet are, it was the whole foot and now it's just the heels, the skin keeps just sort of peeling off and leaving raw skin underneath and my fingers, the joints in my fingers they just keep opening up so I've got sort of open sores. (Fiona)

One woman had made the decision not to have the radiotherapy treatment offered to her when she weighed up the impact it would have on her body and her co-morbid health problems.

But why I turned down the radiotherapy was... I read all the literature, I spoke to loads of people; medical, people who'd had it, people that had not had it, things like that. The side-effects; one, it was, it would have tightened up the skin so the chances of reconstruction were slimmer. I would only have had it on the one side, where the cancer was, and that's the only place it would have stopped it coming back. Also it could cause heart problems, I'm diabetic, and diabetes causes heart problems, why double the risk? Three, it could cause lung problems, I've got asthma, why double the risk of that? It could cause thinning of the bones, I've already got an onset of osteoporosis. And the only way they could treat it is with anti-inflammatories. I'm allergic to anti-inflammatories.... Why take the risk of ending up in a wheelchair. I mean it's like curing of you of one thing and causing another. It's not, the best idea. (Diane)

Making Healthy Changes

Some women reported having made active changes to health behaviours practices since they ended treatment, with the aim of being more in control of looking after themselves and staying healthy. For some this involved making changes to their diet to make it more balanced, others aimed to increase their fitness and lose weight through exercise and some women avoided using chemicals unnecessarily. Those women that had attended the End of treatment group also commented on changes other women had made after ending their treatment.

The other thing I remember having a discussion about, and I did want to find out about, was diet. And it was interesting because you had a lot of people who had gone on to very strict diets, lots of people that had been using homeopathy and herbal, em, you know remedies as well. And again I fit somewhere in the middle, I have cut down on the amount of red meat that I eat, but I haven't cut it out altogether, you know I do, I eat less in the way of processed food because it's just not good for us full stop. Em, but there was quite a lengthy debate about diet, and there were certainly people within the group who had gone for quite... you know, what I thought were quite outlandish diets. But again it's not a criticism, people must do whatever they need to do. (Barbara)

I mean I had hair but very very short and I always had dark hair, I've got grey hair now. Will I get it coloured or will I no, will I get it coloured, or no? I thought no, I'll no put any chemicals or anything like that. And that's another thing as well. I mean I don't know how it thingmay, but they tell you not to use deodorant and things like that... And I've decided, I think there's quite actually... There's two or three people I've spoke to that they have the same as well, em, because someone said there was aluminium or something in deodorant so I've stopped doing that as well. I use body spray but I dinnae use any deodorants or anything. It's just like trying to look after yourself, you know, as best as you can. (Grace)

3.4 Re-defining Identity

Women experienced changes in themselves following their treatment, and needed to re-define how they viewed themselves as part of constructing their “new normal”. This involved focusing on themselves, re-assessing their body image, leaving the cancer identity, increasing their confidence and assimilating the impact of other events.

Focus on Self

Women reported that being faced with their own mortality had led them to realise the importance of their own lives. They acknowledged the need to prioritise their own well-being and focus on looking after themselves, in order to get through their experiences. Some women reported that this was unusual for them, as they had been used to spending their lives looking after others and perhaps compromising their own needs. They often reported that staff had recommended they focus on their own needs and getting themselves well.

And it's one good bit of advice when I was, when I first was diagnosed with [breast care nurse], one of the nurses, she said 'now Anne, now's the time to look after yourself. If you look after yourself you'll get through this', and it always sticks in the back of my mind. And I think you've got to kinda do that. (Anne)

This had permitted women to become less concerned with what they felt they should do, and instead focused on doing what they felt they needed to do, and what best suited them at the time. Also some women discovered new interests or priorities by taking some time to reflect on what they wanted for themselves. Focusing on the self was not at the expense of other people, rather just an awareness that women needed to look after themselves too for their own sake, and their families.

I think you've got to [put yourself first] because nobody else does (*laughs*). So I think I've had to start doing it. I mean there is a lot of people caring, you know, and things like that. But I think once it's finished and you look sort of normal people tend to forget... you know and just thingmay, but. Because I think you do come out a slightly different person than what you went into it sort of thing. (Grace)

One woman described how losing family members to cancer also reinforced to her the need to focus on herself and her own needs.

It was quite difficult and five of them were all cancer, you know.... I had to think to myself well you cannae let this, you know. I'm here and I'm me so I have to get on with my life, what's important. While you're losing members of your family it's not

easy but having said that what can you do? I mean it didn't put me back, it didn't put me down. I mean I was sad what was happening but I just felt I had to get on. You know, I suppose maybe in a way too it maybe makes yourself think you get yourself to the front of the queue, you know how... well sometimes you kind of put yourself back and let everybody else go ahead and then you maybe think to yourself, wait a minute, this is about me now. (Emma)

Body Image

Women all mentioned the impact of their changing appearance both throughout their treatment and in the time following, and how that affected the way they felt about themselves. Some women described feeling as though their hair loss (a side-effect of chemotherapy) was almost like a uniform or badge that branded their identity as a cancer patient. So when women's hair began to return in the time following treatment, this was an important marker in re-defining their identity in the 'normal world' again. Going without their wigs for the first time was a significant event for many of the women.

But again I think it's getting confidence, doing away with the wig... yeah my hair's come in a different colour, different texture and everything, and so I think... People don't bother, actually. So I think because people accept me because I'm me, and I'm still the same person, which I am... And it's a marker of the next stage. I feel like I'm kind of moving forward... it's like all these things... the hospital are away now. You know off with the wig, I'm kinda more, kinda getting back to being natural. (Anne)

Some women had tried their best to maintain as outwardly normal appearance as possible throughout their treatment, learning ways to apply make-up to help preserve the appearance of being 'well'. This was important to them in upholding a positive body image and identity as an individual not a patient. Women also reported that breast changes and weight gain had impacted upon their body image, which left them feeling self-conscious.

Em, I have never ever been a particularly vain person, but I was very very self-conscious. I'd started going swimming again, but I was very self-conscious. I would not wear things that were cut down low. So it was a huge psychological boost in coming in to get the reconstruction done. What I had, to me, was absolutely horrible [after mastectomy]... so what I've got now just feels absolutely fantastic. (Barbara)

A couple of women felt they were looked better following their cancer treatment, and were pleased about changes to their hair and appearance.

My hair is much better as well. My hair's... because I lost my hair obviously with the first lot of chemotherapy. Em, my hair has got a bit more body to it and it feels a bit thicker now and, I mean I've always had my hair short because it was a bit, uch it

never went the way I wanted it, whereas now I'm trying to get it that wee bit longer. (Emma)

And everybody keeps saying your hair is really nice, you know. I say well it's a bit dramatic having to have cancer, so I wouldn't recommend you go and get it all shaved off and try again, you know (*laughs*). (Isla)

Leaving the cancer identity

Although women mentioned their hair returning as being an important marker in the moving on from being seen as a cancer patient, many of them felt unsure about how to manage this element of their identity. Women were aware their cancer experience had impacted on them as a person, but found it hard to integrate that part of themselves into their overall self-view. They needed to construct a new sense of who they were now, which they found hard to describe, but seemed to be an idea of being the same person but different. Women seemed to oscillate between seeing themselves as a cancer patient with all the associations linked to that, and trying to move forward and establish their identity in the 'normal' world.

You see it's difficult as well because you finish your treatment and you don't know... I mean I still don't know yet, how you look at yourself? Because you can say 'well I've had cancer, it's been cut out, they've gave me all the treatment', hopefully to never, for it never to come back. Is that the end of story? you know... And then you sort of change it, well you know you cannae be too complacent you know you've got to be aware sort of thing, ken? So you are thingmying between the two... And then the likes of Maggie's, you know, and the Macmillan nurses, people living with cancer. Does that mean me? Or is that somebody else that's still thingmy? I mean I don't know. No, it wasnae clear and I still feel like that today. You know I'm not clear what my position in life is if you like? (*laughs*). But does anybody? I mean everybody will be the same eh? (Grace)

And again for all of us, it's like we've *had* cancer, we've not *got* cancer... and it's getting around that... I've still got to remind myself that I've not got it. And I think it's when I saw a doctor, I can't remember his surname, and I had an appointment with him and I said something about having cancer. And he said 'no you don't have cancer', he said 'you've had cancer'. I said 'I know'... but it's difficult to try and think that way. Just, I don't know, being me again really... Instead of sort of just being a hospital patient.... (Anne)

Increasing Confidence

Women spoke about the loss of confidence they suffered during their cancer treatment, and their aims to increase this in the time following their treatment. As women had often handed over control and decisions to medical staff during their

treatment, they became less sure of themselves and their own competencies and capabilities. Re-establishing participation in things they were able to do, and becoming more settled in their roles and activities, helped women to create a positive self-image and feel more confident. Some women also identified that having been through their cancer experience made them realise they were a valuable person, which led them to feel more self-assured and take better care of themselves.

But I do feel good about myself now. I mean I don't know em... whether that's right or wrong or indifferent, but I do feel quite an important person, you know and it's important that I look good. I mean I've always put make-up on to go to my work and do that, but I do feel... just silly wee things now, like just to give you an instance, em, like I used to always wear the same chain every day, em, and the same earrings, whereas now I didnae do that, I just go right what am I wearing the day, I'm putting this on the day, I'll have a look in my wee jewellery box at night and I pick something else out for tomorrow. I never done that before, you know. (Emma)

Impact of other events

Some women drew attention to the fact that other changes which occurred in their lives during their cancer experience had also played a role in them re-defining their identities. These changes included being made redundant, becoming a grandparent and being widowed, all of which had a significant impact on how those women viewed themselves. There was also an acknowledgement that the effect of these changes might have been altered or overshadowed by their experience of cancer, which tended to take over in their lives.

Em, the other thing was my husband actually died five weeks before the diagnosis. So it sort of all happened at once. So the beginning part was really, it was bad and yeah... My grandson was born in the middle as well. My first grandchild (*laughs*). So it was quite eh, quite an up and down time right at the beginning. Em, I think it's more the cancer affected how I have felt about the other things really. (*sounds tearful*) I think maybe I pushed... especially my husband's death... I think I sort of, you know, I dealt with it at the time. Yeah. Sorry. (*starts crying*) Yes, I mean that might have happened anyway... Cause I know it takes time, you know, it takes time to sort of... But I think it's more... yeah the cancer sort of took over everything. (Helen)

I'm sure you must get back... to normal. Em, I don't know that life will ever ever... be the same again. It's difficult for me to judge what is normal because a lot of other things happened during that year, so my son and his partner had a baby, and that obviously is a huge life change for you as well. And she arrived, eh, just after I'd had my reconstruction done. So as I was getting better all these other things in my life changed as well. So, normal's different for me. (Barbara)

3.5 Relationships

Women's interpersonal relationships were also of key importance following the end of their breast cancer treatment. They highlighted the emotional impact on other people, the support received from family and friends, increased bonds with other people, negotiating difficulties and contact with other people with cancer.

Emotional Impact on others

Women explained their concerns about the emotional impact on their family and friends, and the efforts they went to in order to minimise the distress of others. They described the stress and emotional turmoil their loved ones went through whilst they were having treatment, which was a source of guilt for some women. As such women tried to protect family and friends after their treatment ended, by putting on a 'brave face' when they encountered any difficulties, in order to minimise any further upset.

However, I just (*sighs*), I felt I had to be strong for my family, you know, em... because I feel bad, if I go down they'll come down with me, you know? And I just kept quite positive and said look I'm going to be ok, you know, so, em... and I have remained positive, em, after I've finished all my treatment. (Emma)

Some women also mentioned concerns about their own children potentially having cancer in the future, and so they wanted to try and protect them from any difficulties they were having.

Well, the very hardest thing of the whole lot was telling my son and daughter, I mean that was really really hard, especially when they were both away. It was... so I suppose in a way I feel more protective of them (*laughs*) and I worry about our daughter too, you know, just in case it happens to her. (Helen)

Support from family and friends

All the women highlighted how invaluable social support was for them throughout their experience of breast cancer. It seemed that women experienced a change in both the level and type of support others offered them after their treatment ended. Most women identified a reduction in the frequency of others getting in touch with them, and that their relationships tended to return more to how they had been before the cancer. For some women this was a relief, as they had felt somewhat overwhelmed by the increase in social contact during their treatment.

It's really funny because when you are first diagnosed it's like everybody must think you are on the way out (*laughs*) and so they are all phoning you, and flowers and whatever. And then phoning you constantly... and then there's kinda a lull and its back to phoning once every three months. Which is good because at least, when they phone you all the time you're thinking well I'm still here, I'm still here. Whereas now it's like back to normal, well for them its back to normal, just how are you and em just catching up really. So there's not this sort of influx of people, just wanting to see me as if it's my last day (*laughs*). Just sort of the way they are, treating me like normal again, like you know, how you would... phone up, how are you and just general... and meeting you for lunch and what have you. Rather than this you're an ill person and we've got to see you and is everything alright and being a bit... too in your face. (Anne)

Other women found this more difficult to adjust to, and felt quite alone without the regular contact with others which they had become accustomed to. It was also clear that women needed to negotiate the level of support they received from loved ones, especially if there was a mismatch in their expectations of one another as outlined earlier.

There are times, since the treatment has finished, I've felt... a bit on my own, should I say. Em, how to describe this?... You know, you've had everybody there, and everybody's been running around after you and looking after you and doing this and doing that and doing the next thing. And all of a sudden.... they're gone. To me that was a bit of a relief anyway... but then there's been odd times when I've thought I could've done with someone. I don't know how to actually explain this (*laughs*). Em, not just to talk to, but just to have someone there.... I just don't know how to describe this feeling really.... (Diane)

Increased bond with others

Some of the women explained that their cancer experience, and the support they received following this, had led to stronger emotional bonds with friends and family. They expressed their gratitude for the extent to which others had helped, supported and cared for them, and the increased closeness this had brought to their relationships.

Well I've got a friend who has been to every appointment with me. She's called my bosom buddy. And we used to try and turn lots of things into treats.... And the bond, I mean we were always very very close, but the bond that we have now is really quite, quite exceptional. She's a very special person. (Anne)

My friend, my best friend... we have been very very close for years now anyway but I think that it's a deeper, more meaningful bond now. I think that having her there through all the treatments certainly makes me... really grateful for having a friend like that. I think you do appreciate it. (Carol)

Negotiating Difficulties

Some women experienced difficulties in their interpersonal relationships following the end of their cancer treatment. Women were occasionally on the receiving end of friends, colleagues or strangers treating them in a way which left them feeling hurt, angry, rejected or disappointed.

My daughter stays up the road, 5-10 minutes away. And I said to her all I was looking for at the time was, because I've got two sets of stairs and you know things like that, a wee hand but... and then I just left it because I wasnae seeing her, so I just left it and then I'm getting the story now that she just couldnae handle it. So I just had to sort of put up with that. (Grace)

Other people were reported to sometimes make insensitive comments, be unable to manage their own feelings about the cancer or be unsure what to say or do which led to them avoiding the women with cancer. This could be difficult for women to cope with.

And there's been a couple of incidents where I've really got quite angry. And, again it was nothing to do with something that I couldn't do or that. I was at work and this wee boy said, 'how come Mum that lady has hair like a man's?' and she went 'it's alright darling she just had a bad haircut'. I said 'excuse me, there but for the grace of god go you, do you honestly think I would have paid for this?' And she looked at me, and I said 'why don't you actually explain to the child why people like me generally like me have hair like this? Instead of telling a pack of lies'. My hair was shorter than this at the time. And my parting shot was 'and apart from that' I says, 'I've got a damn good hairdresser, I don't think you have' (*laughs*). (Diane)

Some women were able to accept this was part of the experience after having cancer, tried not to let it upset them, and instead focused on the more positive relationships in their lives.

Em... some people find it quite hard to sort of acknowledge why I've been away from work or em... em... you know why they haven't seen me around for a while. They don't talk about it, but I think that's fairly normal for people. And I suppose there's some people that, who before would have stopped to chat for a while would now just say well hello and sort of walk by. I mean it's... it doesn't really bother me, you know it's not a problem. It's their problem, not mine (*laughs*). (Helen)

Contact with others with cancer

Women also spoke about the contact they had with other people with cancer throughout their treatment, either in the hospital or at Maggie's Centre. Women seemed to either enjoy and benefit from this contact, or find it difficult and choose to avoid it. Some women established ongoing relationships, and in some cases friendships, with other women with breast cancer. They explained the benefits in

terms of shared understanding and experience, mutual caring for one another and looking at women further through their cancer experiences for inspiration. The transition groups outlined earlier also helped in this regard.

And it's just a funny... I don't think any age, or any sort of time is a good time, but everybody's, I felt that everybody's concerned about everybody else... you know, quite humbling actually. But that's what I felt everybody was sort of caring for everybody else, folk are sort of saying are you alright? And, you don't know whether that's how people were generally or whether it's the illness, that's sort of made them. But I don't know. But I found everybody was quite caring... I think its reassurance they offer me, you know? Em, and its quite nice... em, to speak to people that have gone through it and maybe they're a stage ahead of you and its natural. You know it's not just you, it's not just you. And they are fun as well. (Anne)

For some women having contact with others with cancer provided them with the opportunity to normalise their feelings and experiences and to compare themselves with others. It seemed that being able to make downward comparisons with those less fortunate than themselves helped them to focus on the positive in their own situations after ending treatment.

And I saw some of the other women and heard what had happened to them with chemotherapy... And I'm not too bad, I've come out not too bad because people have... it's actually ruined their lives. Eh, you know the different things that have happened to them. I mean some of them are, I wouldnae say crippled, but you know their feet and their hands are more or less useless because of chemotherapy. And one lady her bowel burst with the thingmy, so she had to go through another major operation and things like that. So though I was feeling rotten at the time, I've come out quite unscathed compared with some people (Grace)

Other women reported a tendency to avoid making contact with others with cancer throughout their experience, as it served as an unwanted reminder of their own situation and vulnerabilities. There was a sense that if they did not immerse themselves in the 'cancer world' then they could pretend that it was not actually real.

Em, I was very wary about going into Maggie's...

{interviewer: in what way?}

I don't know, I suppose because that's for people with cancer isn't it! (laughs) and that couldn't possibly be me. (Barbara)

A couple of women noted that they did not like the notion of sharing their experiences with others, just because they had the same diagnosis, and disliked the attitude other women had towards their illness.

Cause all people wanted to talk about was their treatment, their operations and I thought och (shakes head). It was like a comparison 'oh my operation was bigger

than your operation' sort of thing. And, at the end of the day, it's not a competition. Your.... it's... how can I put this? I don't want to discuss, alright we've been through similar things, but I don't want to discuss my treatment, my feelings, with a complete and utter total stranger. We want... I just wanted to be treated like normal. None of this 'oh well, I've had this done...' and I saw them in there lying down 'oh, oh, oh I'm so ill'. You know, 'oh, I could be dying', and well I'm sorry dear but you will die if you carry on like that.... (Diane)

3.6 Personal Growth

All the women were able to identify positive changes following their experience of cancer, which were incorporated into their 'new normal' lives. These were changes in their priorities and perspectives, having an increased appreciation of life, living for today and positive gains.

Change in Priorities & Perspective

Women spoke about having re-evaluated what was important to them following ending their treatment for cancer. They described a 'life-changing' process of deciphering the key elements of their lives they valued most, and the positive changes they had instigated as a result of this. Most of the women explained that they had increased the importance of spending time with their family and friends, and placed a priority in looking after themselves and those close to them.

So I give her [granddaughter] all my attention, you know... I mean because they are very important to you, your grandchildren, but before I'd maybe be thinking, oh my God I'd better get these windows clean, oh my God. But at the end of the day it just puts everything in its right place. It makes you realise. And like on Sunday when she went away, well it was about 1 o'clock, em, I mean before I would have been flying about like a headless chicken trying to do probably half a dozen jobs whereas I just done what I could do and that was fine, you know. Aye, it does definitely, it's made a different person out of me, which has maybe no been a bad thing, eh (*laughs*)? Aye, it's amazing just what different things it's done to me. I think it just... the wake-up call, you know. It makes you realise how precious life is. You know how important it is. (Emma)

Women also described that having been through the experience of cancer and the treatment gave them a different sense of perspective on events in their current lives. Many women said they were less concerned about day to day hassles and chose not to worry about things which did not matter or they could do nothing about. They used memories of their experience of cancer as a marker against which to measure whether to worry about events.

I thought anything they say can't be any worse than somebody sitting down and saying you have cancer. Em, it was exactly a year to the day from my second chemotherapy and getting my hair shaved off... And it gets everything into perspective. So nothing these people [work evaluators] were going to say, was going to be anywhere near as awful as having dealt with those things. So the very normal, run of the mill things, that upset people no longer upset me. Because... they're not important. (Barbara)

Women also described being aware that they were still adjusting back to life and that it was not worth causing additional stress for themselves, so they would 'let go' things that would normally have bothered them.

So if I wanted my redundancy money, what I had to do was sign a compromise agreement putting away all my rights. So, I mean, there's a few things... like when you've been ill like that it's how far do you go? You know, what can you put yourself through? You know, you want to get back to a normal life as much as possible and put it behind you. I think you've just been through so much that you know, you just say well what is important in life and what isn't. (Grace)

Increased Appreciation of Life

In addition to putting life in to perspective, women explained that their experience of breast cancer had made them more appreciative in general. They felt grateful for small things that they would previously have taken for granted, and were more relaxed and contented. They noted increased enjoyment of daily things that often pass us by and appreciated days when they felt well and were able to do what they wanted to.

One day when I first got back to my work and that and I had eased myself in in a programme, eh, and I was walking back to the car one afternoon and I just thought, ken, life is wonderful, you know, and I'm so glad that I'm alive. You know what I mean? Maybe that sounds a bit corny, but... You know, just, I just wake up every day and think, that's it, it's another, you know another day. But it's no like, it's no dwelling on what's happened in the past, you know what I mean. I just, but I just feel so good. (Emma)

Normal is enjoying the very mundane and ordinary everyday things in life, which suddenly take on a new importance to you. (Barbara)

The women also expressed their gratitude for having received good treatment for their breast cancer and for what some saw as a second chance at life.

These days things aren't as bad as they used to be. People used to, you'd mention cancer and all they could see was a, they had tunnel vision, and all they could see was a coffin at the end of it. And it's not like that anymore. The treatments are so much easier, they are so much better, and the survival rate is a lot higher. (Diane)

Living for today

Women expressed the notion of living in the moment and enjoying each and every day. Some women described things that they had always wanted to do in their lives but had been putting off, and explained that they were now of the philosophy that you should do things now if possible.

You are just prioritising stuff and just, you know, just getting on with your life really. And enjoy the moment (*laughs*). Thing is I was always the one who was saying 'life is precious and live for the moment'. And one of my managers reminded me of that when I had been diagnosed and everything. And I said 'I know, it's funny how you just say things'... just I don't know why I used to say them, but you just sort of say them. But then something like this happens and you think well it is, life is precious. And you just don't know what's round the corner... and just appreciate, appreciate things really and move on, move on. So... (Anne)

In part this notion was motivated by concerns that they might have a fore-shortened future, but some women described having recommended family and friends to do the same and live in the moment.

I mean I'm much, em... I mean yes, you've got to hope there is a future sort of thing. You know it's... I'm probably much more inclined to em... sort of do things rather than put them off. For now. (Helen)

Some women agreed with the idea of wanting to live for today but at the time it functioned for them more as a philosophy than a reality. They were still in the process of regaining their confidence and also seemed concerned that if they planned too much that was positive they might be tempting fate. However they felt confident that they would pursue their life goals in the near future. One woman, who had previously experienced ovarian cancer, explained that she was keen to return to living as she had prior to this episode of cancer, because she had made life changes following her previous episode of cancer, and had already been living for each day.

See I did that years ago. When I had the ovarian cancer everything was... before I had that, I would save for this, save for that, do this, do that, you know. But then afterwards I said live for the day.... And I must admit when I had the ovarian cancer, after everything was over, I had my hysterectomy and everything was over and I was fit again, that's when I decided to spend my savings shall we say, and go and do all the daft things that I always wanted to do. So I've been there, done all that. I mean I went out and I did a parachute jump, I did a bungee jump, I learnt to fly, learnt to fly a helicopter (*laughs*). So I got my pilot's license for that. I drove a formula one racing car. I did the para-assault course... (*whispers*) never again (*laughs*). And I just, I did, I travelled from one side of Canada to the other by train... So, I've done all that. I've done the changes 18 years ago. So I wasn't going to do it again. And my lifestyle that I have, or had before this, suited me down to the ground. And that's

what I want to do, just carry on. So I did my lifestyle changes 18 years ago (*laughs*). (Diane)

Positive Gains

Women wanted to emphasise the fact that they had experienced positive gains after finishing their treatment for breast cancer. They described it very much as a life-changing experience which had provided them with the opportunity to re-evaluate their situation and themselves, and make changes for a more positive future for however long that might be.

I have found the whole thing, silly as it sounds, a very positive experience. You know, that there are people out there who can do this amount to help you in a very serious situation. It gives you a faith in mankind. Em, so in lots of ways I have found it very very positive, and I am a stronger, em, more optimistic person at the end of it... When we discussed the fact that having been through the process left you with some very positive aspects, everybody [in the end of treatment group] agreed with that. There was nobody who didn't feel that in spite of everything, there was a positive gain to be had from the experience. (Barbara)

3.7 Summary of Findings

These findings demonstrate how women construct a new normal life following the end of their breast cancer treatment. Making this adjustment was a very individual experience, yet there was agreement across the women about the domains in which these life adjustments were required. All the women reported adapting to a loss of cocoon, living with uncertainty, regaining control, changes in their identity and relationships and personal growth as essential themes in their lives post-treatment. There did not appear to be a staged process in which women adjusted to these domains, as each woman experienced and responded to them differently and at different times. Many of the themes were interrelated and impacted upon one another, and all combined together to form the overall journey of women from end of treatment onwards. As Anne describes, these categories explain the ways in which women gradually piece their lives back together after breast cancer.

I'm just sort of glad like everything's over. And it is like a recovery, I know that, when I got that stuff sent by [breast care nurse] it said recovery. But it is a recovery in a way, without being melodramatic. Because my breast is repairing itself, you are physically getting fitter, you are getting your self-confidence... So it's just putting parts of that jigsaw that have not been quite, they have been there, but they have not been quite sealed together. Putting them all back together again and then you would end up being normal again, I would say... Whatever normal is (*laughs*).... (Anne)

4. PERSONAL REFLECTION

Qualitative researchers advocate the use of a reflective diary throughout the research process (Burck, 2005; Charmaz, 2006). I kept a diary of my thoughts, concerns and feelings whilst conducting my research interviews and undertaking the analysis, in order to understand better my influence in the research. Smith (2006) recommends that researchers include some examples of their self-reflection in their qualitative reports. As such I have included some of the key themes from my diary.

My initial anxiety about undertaking my first qualitative research study was evident in early diary entries. These initial concerns ranged from general concerns about the interview style (e.g. ensuring questions are phrased in an open-ended manner) to specific worries within the interview setting (e.g. repeatedly glancing over to check the voice recorder was still working).

After the first few interviews, however, I relaxed and began to feel more confident about the research process. This was helped by transcribing my interviews and realising there was lots of rich data, by gaining reassurance from my supervisors about my interview style, and by women reporting at the end that they had found the interview helpful.

“I felt much more relaxed in today’s interview and really quickly got immersed into her story. [Participant] appeared to be really engaged in the process and seemed to be enjoying having the opportunity to share her experience. When we were walking back out after the interview [participant] said she thought it had helped her to discuss her feelings with me and was pleased she had taken part. The fact that she found the interview beneficial has helped me feel more confident.” (28.03.08)

Following this my diary entries became more focused on how I was managing some of the tensions in the research process. One such tension was negotiating how to place myself in the role of the ‘naive’ researcher when I had clinical experience working as a Trainee Clinical Psychologist with women with breast cancer. I spent time deciphering what information I would not have known (e.g. about treatment regimes, physical side-effects, possible psychological impact of ending treatment) prior to commencing my clinical role. This helped to ensure that I asked women for further details, rather than going on the assumption that we had a shared

understanding about these issues. Over time, however, I accepted that my background knowledge of the area probably helped me to form a better rapport with women as it confirmed to them my interest in the research question and their stories. I also found it challenging maintaining my role as researcher, rather than clinician, if women were describing upsetting events which cause them difficulties. It was important for me to ensure women were happy to continue with the interview process, without feeling I was trying to stop them discussing emotive issues.

My research diary entries also commented on the tension between establishing rapport with women and needing to undertake certain research formalities. This was especially marked when interviewing women at home. They would often start relaying their stories to me as soon as I arrived, which meant I had to find an appropriate way to interject to discuss informed consent and set up the recorder.

“It was frustrating this morning at [participant’s] house. She was making herself a drink before we started the interview and described her philosophy on breast cancer in such an eloquent way that it really made me stop and think. Although she talked about this again during the interview it was not in quite the same way, and I can’t remember how she put it. I only wish the tape recorder had been on.” (29.04.08)

It was also important for me to create a balance between facilitating women’s engagement by following their story and what they felt was important, and keeping the interview somewhat related to the research question. I appreciated that it was important for women to tell me the story of their cancer journey from diagnosis (or even pre-diagnosis) onwards, so that I would understand the context for their experience of ending treatment. Asking women to elaborate on details within their stories helped them to access how they were acting, thinking and feeling at this time and take them back to their experiences rather than reflecting too much upon them. Another theme that came from my research diary was that of ensuring I was reflecting back what women were telling me enough to validate their experience and clarify I was understanding them, but not too much so that it might appear I was leading their narrative. After doing more interviews I began to realise there was no such thing as a perfect interview, and became more confident in my own interviewing style.

It was interesting to reflect on the impact of conducting research interviews both in women's homes and in my clinical room at the cancer centre. Perhaps attending the cancer centre triggered women's memories of their cancer experience and made the interview feel more formal and less in their control. Perhaps interviews at home helped women be more relaxed and confident, yet provided more opportunities for distraction and interruptions. Although it is likely these factors influenced the interviews, women seemed engaged in both settings and I adapted to each situation to ensure women felt as comfortable as possible.

Another important theme in my diary was thinking about the analysis, and the potential impact of my clinical role with women with breast cancer. In addition to the knowledge I have gathered about breast cancer treatment, I was aware of being better able to manage the emotional impact of women's stories than when I had first started working in Oncology. There were some aspects of women's stories which I found very touching and poignant, however I felt I might be somewhat desensitised to finding them upsetting compared to those who have not worked in this field. This was demonstrated to me when my supervisors reported finding themselves feeling upset by some parts of the interview transcripts.

"It really helped talking through my transcript with [supervisor] today and hearing their thoughts. I was struck by how emotional they had found it, and that they found themselves welling up when [participant] described the strength of relationships with others with cancer. It reminded me of how I first felt working at the Breast Unit and how, through my 'oncology-tinted' glasses, I've become less affected by people's stories. I suppose I have maybe been more struck by the positives in the interviews, which I don't hear as much of in my clinical work." (01.04.08)

Throughout my research diary there is a theme of being pleased to have taken on the challenge of conducting my first piece of qualitative research. Not only has it been a privilege to have women share their personal journeys with me, but it has been rewarding that they too have found it a beneficial experience.

5. DISCUSSION

This chapter discusses the current research findings with reference to relevant clinical and theoretical literature. The methodological limitations and strengths of the study are highlighted. In addition, the theoretical and clinical implications of this study are outlined, as are suggestions for future research.

5.1 Constructing a New Normal

This study aimed to better understand the experiences of women who had ended treatment for breast cancer. The findings showed that the end of treatment was a specific event in women's cancer journey, which required adjustment and transition. Women managed this by altering key domains in their worlds, in order to construct a new normal. There was broad agreement across women about the domains; loss of cocoon, living with uncertainty, regaining control, re-defining identity, relationships and positive growth. These will now be discussed in turn.

Loss of Cocoon

Previous research has shown that women report finding the end of treatment distressing, with levels of anxiety and depression increasing (Ward *et al.*, 1992; Culver *et al.*, 2002). Experiencing a loss of cocoon encapsulated the sense of loss women felt at the end of treatment. Women had been surprised that they experienced distress at this time, and many felt staff had not adequately prepared them for this reaction. However it is important to consider that most of the women attributed these feelings to adjusting to the end of their treatment, rather than to significant psychological difficulties. This suggests that feelings of post-treatment distress might be relatively common and women should be prepared for these in advance. Another component of this loss was the perceived abandonment some women encountered following reduced contact with their medical team. The loss of relationships with staff has also been highlighted in previous studies, with descriptions of women feeling "cast adrift" by medical staff (Lethborg *et al.*, 2000). Some women reported uncertainty about whom they could contact at this time, which is consistent with the

SIGN (2005) guidelines which highlighted the variations in ongoing contact women had with their breast care nurse.

The 'transition' groups, attended by women in this study, helped reduce the impact of the loss of cocoon and facilitate women's adjustment to their new life without regular hospital contact. Although previous literature has demonstrated the benefits of both support groups and exercise (Docherty, 2004; Hewitt *et al.*, 2005), it has not been identified that having post-treatment exercise groups is beneficial for providing a link between the cancer world and 'normal' life, which highlights the need to research this further.

Living with Uncertainty

The uncertainty of life after cancer was evident in all the women's experiences. Fear of recurrence was an ever-present concern, which has been well documented in the literature (Baker *et al.*, 2005; Stanton *et al.*, 2005). The theme of losing trust in one's body seems to be similar to the theme in Breaden's (1997) qualitative study of 'the body as a house of suspicion'. Women tried to cope with these fears of recurrence, and ultimately death, by consciously choosing to avoid these thoughts, put them to the back of their minds, and distract themselves. Overall this appeared to be an adaptive coping strategy for most women, however there was some suggestion that at times women were unable to distract themselves from intrusive thoughts about their cancer. This seems to fit with the proposition that women can experience some symptoms of post-traumatic stress disorder following their treatment (Alter *et al.*, 1996). Using positive thinking seemed to be another way in which women coped with their fears and provided themselves with an optimistic view of their situation. Interestingly, previous research has shown that women commonly mention having a positive attitude as an important factor in preventing cancer recurrence, which might encourage them further to focus on the positive (Stewart *et al.*, 2001).

Regaining Control

Women reported needing to find ways to regain control following the end of their treatment. Previous research has demonstrated that women who feel a loss of control

experience higher distress and poorer adjustment, and women with higher levels of perceived control report fewer depressive symptoms (Lowery *et al.*, 1993; Newson *et al.*, 1996). To enhance their sense of control, women often needed to adjust the expectations placed on them, by self and others, about what they were able to manage. These findings are in agreement with existing literature, which shows that women often have unrealistic expectations about the speed of their own recovery post-treatment (Bumpers *et al.*, 2002; Winterling *et al.*, 2008). Ongoing physical side-effects of treatment continued to be problematic for women for longer than predicted, both in this current study and previous research (Beisecker *et al.*, 1997; Stanton *et al.*, 2005). Women in this study found that making healthy changes in their lives helped them to feel more in control of their current and future health, which fits with Costanzo's (2006) suggestion that the months after treatment ends are an ideal time to encourage women to make adaptive changes in their health practices. Women are more likely to implement healthy changes if they believe it will reduce the chance of recurrence (Rabin & Pinto, 2006). Regaining control through returning to valued life roles was also important for women, especially if these roles had disrupted or suspended during treatment, as demonstrated by previous studies (Bouknight *et al.*, 2006; Northouse *et al.*, 1998). It has been shown that returning to work is an important component of quality of life for people who have had cancer (Main *et al.*, 2005), even if they have reduced their working hours or ambition (Joly *et al.*, 2000; Stewart *et al.*, 2001).

Re-defining Identity

Women experienced changes in the way they viewed themselves after treatment. It has been highlighted in the literature that women are often unsure about their cancer 'status' following treatment (Costanzo, 2006), and this was found in the current study because women were coming to terms with leaving their cancer identities. They were also adapting to their new physical status and resultant body image, and finding ways to increase their self-confidence in their new-found identity. Fobair *et al.* (1996) also noted that women had to make changes after breast cancer treatment as they had not returned to their 'pre-diagnosis selves'. The current study also discovered that other events in women's lives, like the death of a partner or birth of a

grandchild, had impacted on their self-image after cancer treatment, a finding which is not mentioned in previous research.

Relationships

Women reported negotiating changes to their relationships following the end of their treatment. It is recognised in the literature that cancer has become a 'family disease' as its impact ranges far beyond the individual (Rolland, 2005; Rowland & Baker, 2005). Women felt concerned about the emotional impact of their cancer on family and friends and worried about imposing further stress on them after treatment ended, as also found by Harvey (2005). However, women did acknowledge how invaluable social support was, both from those already in their support networks and, for some, from other women with breast cancer. The benefit of emotional and informational support has been well documented in the literature (Chantler *et al.*, 2005; Holland & Reznik, 2005). Some women encountered interpersonal difficulties with loved ones after treatment, which echoes Lewis *et al.*'s (2008) reports of spousal distress and marital tension. Stanton *et al.* (2005) also recognised the need for women to make adaptations in their interpersonal relationships as part of their post-treatment adjustment. There was a sense that women in the current study who relied more on supports in the 'cancer world' had less well-established community support networks and, therefore, found it harder to negotiate changes to their relationships after the end of treatment. This possibility warrants further investigation, as this cohort might be more vulnerable to experiencing difficulties if they are unable to access sufficient support.

Personal Growth

There is evidence in the literature that women experience positive life changes following cancer treatment (Foley *et al.*, 2006; Leedham & Ganz, 1999). The women in this study reported that, having faced the possibility of death, life took on new meaning for them and they experienced a sense of post-traumatic growth (Janoff-Bulman, 2004; Tedeschi & Calhoun, 1996). Women became more appreciative of life and tried to live for the day, life changes which were also demonstrated in the research of Stanton *et al.* (2005). The literature also suggests that increased life

satisfaction can help compensate for unfulfilled expectations about regaining full functioning post-treatment (Kessler, 2002).

Journey to New Normal

The women in this study acknowledged that after having breast cancer life would not be the same again. After ending treatment, there was a need to adjust and assimilate their experience, which was achieved through constructing a new normal. It has been suggested in the mental health literature that recovery is not about returning to one's former functioning, but rather is about a "self-directed process of transformation" (Deegan, 2001, p5). This definition applies well to the experiences of the women in this study. Although they all undertook adaptations in the same life domains, they each placed different levels of importance on different domains at different times. As such, they each directed their own process, or adjustment, to achieve their own new normal. There did not appear to be a staged process which women worked through in order to reconstruct their lives, although many of the categories or domains were interlinked. There were, however, some important common landmarks across women's experiences, such as getting their hair back and feeling ready to return to work.

It is interesting to speculate on factors that might influence how women experience these domains in different ways, for example could it be linked to their personality, attachment styles, previous experience of illness, social support networks, prior quality of life? Understanding the influence of these factors would add to the understanding of women's experience of ending treatment for breast cancer, and would be a worthy area for future research.

5.2 Methodological Consideration

This section outlines the methodological strengths and limitations of this study, which should be taken into consideration when interpreting the findings.

Limitations of Study

The methodological limitations of the study include sampling bias, the use of single research interviews, link with the Breast Unit, theoretical sampling, theoretical saturation and the simplification of women's experiences.

Sampling Bias

The inclusion criteria for the study biased the sample to women with specific disease types, prognoses and treatment regimes. There was further selection bias when the BCNS team highlighted which women were appropriate as potential participants. Furthermore the women who participated were self-selected and may have been those that were particularly affected by the end of treatment, or those who felt they had processed and adjusted their experiences enough to talk about them. Unfortunately no information was available on the women who did not volunteer to take part. It is acknowledged that this bias limits the generalisability of the current findings, however they could be used to derive hypotheses for larger quantitative studies of women with breast cancers to test whether they are representative of a larger population.

Single Interviews

It has been argued in the literature that conducting single research interviews can lead to a somewhat superficial view of participants' experiences, as they might try to present their accounts in a publicly acceptable way (Charmaz, 2006). Conducting multiple interviews may have been beneficial in increasing rapport with women and socialising them into the research style. This may have facilitated greater insight and reflection, and encouraged women to discuss more sensitive issues (Mathieson, 1999). For example, sexuality and fertility issues were not mentioned in this study, but have been in the literature (Helgeson & Tomich, 2005). Conducting interviews at several time points from end of treatment onwards would have given more immediate, and perhaps more accurate, accounts of women's experiences over time. The current study relied on women to accurately recall the end of their treatment retrospectively, which might have resulted in them forgetting important aspects of the process. However the use of multiple interviews was not feasible within the

timescale of this study, and the additional demand on participants' time might have impacted on recruitment.

Link with Breast Unit

It is possible that women's awareness of my association with the Breast Unit team impacted on their narratives. Crow *et al.* (2002) draw attention to the fact that participants tend to respond positively and express satisfaction if they wish to continue using a service. As women felt grateful for the service which had effectively saved their lives, and knew they would continue to attend for follow-up, it was possible that women would not want to appear critical. However, prior to the interview, I explicitly requested women to be as honest as possible, explaining that hearing both positive and negative experiences would encourage developments in service. This appeared to help women respond truthfully, and many suggested possible improvements during the course of their interviews.

Theoretical Sampling

As outlined in the method chapter, Strauss & Corbin (1998) recommend that as data collection proceeds, researchers should focus recruitment on specific participants who might contradict or expand the developing theory. This was not possible, unfortunately, because insufficient information was available about potential participants for me to target recruitment. I did, however, encourage the BCNS team to invite all women who met the inclusion criteria to participate, even if they felt the women had negative or unusual experiences of ending treatment. I also incorporated concepts from earlier interviews into subsequent ones (after women had offered their own thoughts) to aid category generation, which is a suggested alternative to full theoretical sampling (Janesick, 2002; Strauss & Corbin, 1998).

Theoretical Saturation

Theoretical saturation refers to the point at which further data collection reveals no new properties or insights about the theoretical categories or emerging grounded theory (Charmaz, 2006). There is much debate in the literature regarding the concept of theoretical saturation, and whether it can ever realistically be achieved (Dey,

1999; Willig, 2001). Constructivist grounded theory, in particular, places much less emphasis on saturation than earlier versions (Charmaz, 2006). As such, this study did not aim to reach theoretical saturation, but I do acknowledge there was a high degree of consistency within the categories across women's narratives which were constructed with me as researcher.

Simplification of Experience

Although a constructionist grounded theory analysis avoids some of the pitfalls of positivism, it is acknowledged that it will still unavoidably reduce the complexity of women's lived experiences of ending treatment for breast cancer. As noted by Breaden (1997), identifying themes in participants' accounts is, at best, a simplification of their whole experience. It is accepted that themes only emerged in the data through my identification and interpretation of them. As such, the presented grounded theory is not claimed to be the only possible, or the correct, interpretation of the women's experiences. As van Mahen notes:

"A phenomenological description is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper description." (van Mahen, 1990, p31).

Strengths of Study

There are a number of methodological strengths in this study, which include communication with Breast Unit staff, methodological rigour and giving women a voice.

Communication with Breast Unit Staff

The good working relationships I have established with many of my colleagues in the Breast Unit were helpful when undertaking this study. Although, as outlined earlier, this may have been a limitation in some respects, it was also a methodological strength because it enabled the research to go ahead in the first place! Also undertaking a study of clinical relevance meant the BCNS team were motivated recruiters. My involvement with the Breast Unit also enhanced my compassion for

women and their stories, which may have improved rapport (as discussed in the personal reflection chapter).

Methodological Rigour

Undertaking qualitative research for the first time I concentrated greatly on adhering to the methodological steps as much as was feasible within the scope of this study. I paid close attention to validity issues to try and ensure the “trustworthiness” of my grounded theory (Lincoln & Guba, 1985). Investigator triangulation was carried out, through discussion about coding of transcripts and generation of categories with my supervisors and clinicians in psycho-oncology (Jamieson et al., 2007). Member checks were carried out, where women were asked to confirm their agreement with the themes generated from their interviews (Flick, 2002). Information about the research context and participants has been provided to assist the reader in deciding whether the findings could be transferred to their own setting (Stiles, 1999).

Giving Women a Voice

This study provided a voice to a group of women affected by their experience of ending breast cancer treatment. The qualitative research interview provided them with the space to describe the intricacies and complexities of their experience, and to feel understood. The study has also ensured their stories are shared with others, with the hope of helping improve services for women who end treatment after them. Many of the women said they benefited from reflecting on their experience, and research has shown that reflection can help people assimilate and accommodate their experience and aid recovery (Coleman, 1999).

5.3 Theoretical Implications

This section considers how the findings of the current study relate to the theoretical models of coping and adjustment outlined earlier.

The experience of constructing a new normal appears to fit within Folkman's (1997) cognitive mediational model of stress and coping. Women's interpretation of the end of treatment as an event with unexpected challenges leads them to employ a range of coping strategies. These include regaining control over practical concerns (problem-focused coping), managing their feelings and negotiating social support (emotion-focused coping) and focusing on the positive and changing their priorities (meaning-based coping). These coping strategies help women to adjust to their new normal lives and manage the ongoing stress of fear of recurrence.

Moorey & Greer's (2002) cognitive model of adjustment to cancer can also account for some of the findings in this study. Women's beliefs about and expectations of life after cancer treatment, along with their personal schema about themselves and the world, can impact upon their thoughts, feelings and behaviours post-treatment. The cognitive and behavioural strategies which women then employ to construct their new normal can be explained by this model. It also provides the means to explain how individual characteristics and past history can influence this process. However it is unclear how women's experiences of changed identity, relationships and personal growth would fit within this model.

Brennan's (2001) Social-Cognitive Transition Model of adjustment emphasises the ongoing nature of adjustment. As such, the idea of women adjusting to the end of treatment by constructing a new normal, could fit with this model. Women's expectations of returning to normal could be viewed as assumptions which are likely to be shattered by their experience that ending treatment is not the end, which results in the distress women encountered. Women then adjust their assumptions about their lives and construct new mental models of how they want things to be within the limitations imposed on them by their cancer experience.

Women's experiences of constructing a new normal after breast cancer treatment can be incorporated by these models as described above. Yet the very broad focus of these models means that they can accommodate a wide range of experiences. They

do not mention end of treatment for cancer as an event in its own right, nor do they highlight that it is a stage of the cancer journey that requires adjustment.

The findings of the current study do appear to fit relatively well with Stanton et al.'s (2005) model of post-treatment adjustment. The categories which are part of constructing a new normal can be incorporated in to the wider themes of emotional domain, physical health, interpersonal relationships and life perspective and practical concerns, which are said to be influenced by individual's circumstances and their appraisal and coping. The results of the current study add to the model presented by Stanton and colleagues, by giving more detail about the ways in which these life domains are affected and the types of adaptive changes women need to make after treatment. Further research could investigate how robust and generalisable the current findings are and, if appropriate, a new theoretical model of post-treatment adjustment could be developed.

5.4 Clinical Implications

Whilst acknowledging the limitations of this current study, the findings do suggest a number of potential implications for clinical practice with women ending treatment for breast cancer.

Education

Healthcare professionals working with women who have breast cancer need to be aware of their experiences of ending treatment. It is important that staff appreciate the process of adjustment women undergo, and are aware of the life domains that can be affected. Staff training could be undertaken to facilitate understanding of this aspect of women's cancer journeys. It would then be possible for staff to ensure that women in their care are well prepared for the challenges that might face them post-treatment. This could involve normalising and validating the feelings women might experience, providing them with information about managing concerns and encouraging them to have realistic expectations and set realistic goals. Women could

also be encouraged to discuss their feelings about having reduced contact with medical staff with whom they have formed relationships. Being prepared for loss can facilitate the process of moving on. Ensuring a smooth transition of care back to general practitioners, perhaps by arranging end of treatment reviews for breast cancer patients, could aid women's adjustment. As Schnipper, a breast cancer clinician and survivor, emphasised, medical staff should;

“prepare their patients for the post-traumatic period with the same detail, empathy, and attention that was given to the earlier explanations of diagnosis and treatment planning” (Schnipper, 2001, p3581).

Intervention

Further interventions could be established to facilitate women's adjustment. Clear information on managing physical side-effects including fatigue, pain and menopausal symptoms, should be provided to all women prior to the end of their treatment. As women might consider making healthy changes at this time, advice about diet, exercise and reducing alcohol or tobacco intake could also be helpful.

The provision of psycho-education could facilitate women's adjustment and construction of a new normal. Increasing women's awareness of cognitive and behavioural strategies such as goal setting, pacing of activities and positive reframing would help them to regain control over their lives and return to valued roles and previously enjoyed activities. Women could also be taught strategies for managing fear of recurrence including acceptance, distraction, putting it to the back of one's mind and focusing on the positive. Interventions could also focus on enhancing women's well-being, increasing their confidence and body image, and encouraging reflection about the positives in their lives. These psycho-education interventions could be delivered in a group setting or on an individual basis, and undertaken by Breast Care Nurses with supervision from Clinical Psychology Services (SIGN, 2005). Alternatively, a self-help guide or workbook could be developed for women to use after breast cancer treatment to facilitate their construction of a new normal. Involving family and friends would give them a better appreciation of how women feel after treatment, and help everyone accept that things will not 'return to normal'.

Increased availability and variety of 'transition' groups would also be beneficial, with evening groups for those women who have successfully returned to work. There could be a range of groups to appeal to different women including exercise, relaxation, creative writing, anxiety management (with evaluation to assess whether they are effective). In addition, regular expert patient-led support groups could be established for women who want ongoing supportive contact with other women who have had similar experiences. Perhaps holding these in community settings would further facilitate women's adjustment.

Given the vital role of social support in women's adjustment post-treatment, it is important to ensure that their family and friends also have adequate support and the opportunity to process the emotional impact of the cancer on them. It might be beneficial to run a group solely for family and friends to allow them to share experiences and address their concerns without women with breast cancer present.

In addition to group interventions, it is necessary to provide individual support and assistance to those who prefer it, especially for those who choose not to have contact with other people who have had cancer. Individual end of treatment review meetings with women's Breast Care Nurses could be successful, as women in this study found reflecting on their experiences helpful.

Training and Supervision

In order to establish and monitor these groups it would be important for Breast Care Nurses to have appropriate training in psycho-education techniques and to have access to regular supervision for advice and support. It would also be important to consider the emotional impact on staff of addressing these losses with women, especially if they have formed relationships with them throughout treatment, and reflective practice could be encouraged during supervision. This could be undertaken by Clinical Psychology Services, and would also facilitate identification of women who were experiencing psychological distress and required referral for individual psychological input.

5.5 Future research

A number of potential research studies could build on the findings of this current study. Conducting a series of interviews with women prior to ending, at the time of ending and in the weeks and months that follow would improve our understanding of women's experiences and provide the opportunity to investigate how adjustment changes over time. A study incorporating women with different prognoses and treatment regimes would allow comparison to see whether the current findings are applicable to other breast cancer patients. It would also be interesting to re-interview the women in the current study again in the future, to see how they have adjusted to their new normals. It might also be interesting to investigate the experience of men who have had treatment for breast cancer, as they may confront additional or different challenges in constructing a new normal. Research could also be conducted with people with other types of cancer, to see if they have similar experiences following the end of their treatment.

A quantitative study could also be developed in order to investigate whether the current findings are generalisable to a larger population of breast cancer patients. Research could also be conducted to generate an appropriate measure of end of treatment adjustment, which might incorporate dimensions on, amongst other things, mood, fear of recurrence, relationship functioning, self-confidence, quality of life, personal growth, locus of control. This would be beneficial for future research into what factors influence end of treatment distress and coping. It would also be a helpful clinical tool to allow practitioners to monitor women's psychological adjustment following the end of their treatment, and provide intervention where appropriate.

Future research might also try to decipher what affects the way in which women appraise and adjust to the end of treatment. A number of factors that could warrant further investigation could include attachment style, personality, coping style, prior life satisfaction and self-esteem.

Randomised controlled studies could also be designed to research the potential benefits of interventions for women at the end of treatment. These could include looking at the impact of increased communication skills training for staff, better preparation for the end of treatment, individual review meetings to reflect on cancer experience, transition groups incorporating anxiety management and confidence building as well as exercise and self-help interventions on constructing a new normal.

5.6 Conclusion

The end of treatment is an important stage in women's cancer journey, which requires adjustment in a number of life domains. It is important that this is identified and normalised, and that women are given space to negotiate this transition, whilst they construct their new normal.

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7.APPENDICES

Appendix 1	Invitation Letter	112
Appendix 2	Participant Information Sheet	113
Appendix 3	Participant Consent Form	115
Appendix 4	Letter to Consultant & GP	116
Appendix 5	Ethics Committee Approval	117
Appendix 6	Research & Development Approval	119
Appendix 7	Interview Guide	121
Appendix 8	Sample of Transcription and Coding	122
Appendix 9	Example of Early Diagram – Early Themes	128

Breast Unit
(Address)

(Participant's Address)

(Date)

Dear Ms (Participant's Name),

Re: Research Study – “A qualitative study of women's experience of ending treatment for breast cancer.”

The above research study is being carried out in the Breast Unit, and I thought you might be interested in taking part.

The study aims to gain a deeper understanding of women's personal experiences of ending treatment for their breast cancer.

The study is being carried out by Karen Forrester, Trainee Clinical Psychologist, who works in the Breast Unit and is doing the research study as part of her training.

I have enclosed an information sheet which explains more about what the study is about and what would be involved if you choose to take part.

If you would like to ask any further questions about this study, or would like to take part, please contact Karen Forrester within the next two weeks. Her contact information can be found on the accompanying information sheet.

Many thanks for taking the time to read this information.

Yours sincerely

(Breast Care Nurse's Name)
Breast Care Nurse

A qualitative study of women's experiences of ending treatment for breast cancer

I would like to invite you to take part in a research study. Before you decide if you want to be involved it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with others if you wish. You are also welcome to contact me if anything is unclear or you would like further information. Please take time to decide whether or not you would like to be involved. Thank you for taking the time to read this information.

What is the purpose of the study?

The study aims to try and understand the experiences of women who have ended their main treatments for breast cancer (surgery, chemotherapy and radiotherapy). I am interested in finding out how women feel about ending their treatment and also how they manage in the months afterwards. I am aware that this can be a difficult time for some women, and others prefer to put their thoughts of cancer treatment behind them. I am keen to interview a range of women who have had different experiences, whether positive or negative.

Why have I been asked to take part?

You have been invited to take part as you have recently finished your treatment for breast cancer at the Cancer Centre. Approximately 10 other women will be taking part too.

Do I have to take part?

It is up to you to decide whether you want to take part. If you choose to then you will have the opportunity to ask questions and will then be asked to sign a consent form to show you have agreed to take part. You are free to withdraw from the research at any time without giving a reason. A decision to withdraw, or not to take part, will not affect the standard of care you receive.

What will happen to me if I agree to take part?

Once I know you are willing to take part I will contact you to arrange a suitable time for us to meet. The interviews can either take place at the Cancer Centre or in your home, whichever suits you best. I will be interviewing women on their own, but you could have a family member or friend with you if you would prefer. The interview is likely to last about one hour and I would like to audiotape the interview so that I can remember everything that is said. During the interview I will ask you about how you felt about ending your treatment, how things have been since then and if anything has made this time easier or more difficult for you. I would also be really interested to hear anything else you think is important about ending treatment.

After the interview you would have the opportunity to ask any questions and discuss how you felt about the interview.

Please note there is unfortunately no funding available to cover your travel expenses.

Will my taking part in the study be kept confidential?

Yes, I will follow ethical practice and all information about you will be handled in confidence. The tapes of your interview will be stored in a locked filing cabinet which only my research supervisors and I can access. When I type out our interview all your identifiable personal information will be removed and the transcript will be given a code number. You will not be able to be identified from the results of the study. All the audiotapes will be erased once the study is finished. I will write to your Consultant and your GP to let them know you were involved in the study, but will not give them any information about what we discussed during our interview.

What will happen to the results of the study?

The results of the study will be written up in part fulfilment of my degree of Doctorate of Clinical Psychology at the University of Edinburgh. An article might also be published to allow other professionals to learn from the results of this study.

What are the potential benefits or risks to taking part?

I hope that this study might help you by providing you with the opportunity to have your views heard. I also hope that the information I get from this study might help improve the treatment of other women who have breast cancer.

There should be no risks associated with taking part in this study, as you do not have to share any information you do not want to. You may also stop the interview at any time if you feel uncomfortable or upset. You will also be given the opportunity to be referred on the Clinical Psychology Service to Oncology following the study should you wish.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Research and Ethics Committee. It has also been approved by the University of Edinburgh and staff at the Cancer Centre.

Contact Information

If you would like to ask any questions about the study, or would like to take part, please get in touch with me.

Karen Forrester
Trainee Clinical Psychologist

Telephone:

E-mail:

Consent Form**A qualitative study of women's experiences of
ending treatment for breast cancer**

1. I have read and understand the Participant Information Sheet (version 2).
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
4. I give consent for my interview to be audiotaped and transcribed onto computer.
5. I give consent for my Consultant and GP to be made aware of my participation in this research study.
6. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Signature	Date

_____	_____	_____
Researcher Name	Signature	Date

Cancer Centre
(Address)

(Consultant's Address)

(Date)

Dear Dr (Consultant's Name),

Re: Research Study "A qualitative study of women's experience of ending treatment for breast cancer."

I am writing to inform you that (Participant's Name) volunteered to take part in the above research study. This involved her meeting with me for an interview on (Interview date), to discuss her experience of ending treatment for breast cancer.

Yours sincerely

Karen Forrester
Trainee Clinical Psychologist

cc. Participant's GP

18 February 2008

Miss Karen E Forrester
Trainee Clinical Psychologist

Dear Miss Forrester

Full title of study: A qualitative study of women's experience of ending treatment for breast cancer (V1)
REC reference number: 07/S1104/38

Thank you for your letter of 07 February 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by the chair on behalf of the meeting.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		07 November 2007
Investigator CV	CI	01 November 2007
Investigator CV	Educ supervisor	
Protocol	1	01 November 2007
Compensation Arrangements		20 July 2007
Interview Schedules/Topic Guides	1	07 December 2007
Letter of invitation to participant	2	07 February 2008
GP/Consultant Information Sheets	1	01 November 2007
Participant Information Sheet	2	07 December 2007
Participant Consent Form	1	01 November 2007
Response to Request for Further Information		07 February 2008
Caldicott Guardian Authorisation - Access to Scan Audit		04 February 2008
letter confirming univ student	letter confirming Univ student	01 November 2007

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from <http://www.rdforum.nhs.uk/rdform.htm>.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

- a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.
- b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk.

07/S1104/38	Please quote this number on all correspondence
--------------------	---

With the Committee's best wishes for the success of this project

Yours sincerely

Chair

24th January 2008

Miss Karen Forrester
Trainee Clinical Psychologist



**RESEARCH &
DEVELOPMENT
OFFICE**

Dear Miss Forrester

MREC No:	N/A
CRF No:	N/A
REC No:	07/S1104/38
R&D ID No:	2007/W/PSY/06
Title of Research	A qualitative study of women's experience of ending treatment for breast cancer (V1)
Protocol No/Acronym:	Protocol Version 1 dated 1st November 2007

The above project has undergone an assessment of risk to NHS and review of resource and financial implications. I am satisfied that all the necessary arrangements have been set in place and that all Departments contributing to the project have been informed.

As this is a single site project involving patients and led by you as a University employee, NHS agrees to act as Co-Sponsor with University of Edinburgh.

On behalf of the Chief Executive and Medical Director, I am happy to grant management approval from NHS to allow the project to commence, subject to the approval of the appropriate Research Ethics Committee(s) having also been obtained. You should note that any substantial amendments must be notified to the relevant Research Ethics Committee and to R&D Management with approval being granted from both before the amendments are made.

Please note that under Section A, Q35, NHS provides indemnity for negligence for NHS and Honorary clinical staff for research associated with their clinical duties. It is not empowered to provide non-negligent indemnity cover for patients. NHS does not provide indemnity against negligence for healthy volunteer studies. This is the personal responsibility of both NHS and honorary employees and is usually arranged with a medical defence organisation or through the University of Edinburgh.

This letter of approval is your assurance that NHS is satisfied with your study. As Chief Investigator or local Principal Investigator, you should be fully committed to your responsibilities

"Improving health through excellence and innovation in clinical research"

within the Research Governance Framework for Health and Community Care, an extract of which is attached to this letter.

Yours sincerely

**Professor
R&D Director**

**Enc Research Governance Certificate
 Tissue Policy (if applicable)
 MTA (if applicable)**

☒ (to be signed and returned)

☐

☐ (to be signed and returned by the recipient of
Tissue)

Copies *Administrators, Research Ethics Committee*

**A qualitative study of women's experiences of
ending treatment for breast cancer**

Introduction to Interview:

Thank you for agreeing to take part in this interview. You are participating on a voluntary basis and are free to change your mind and end the interview at any time, without having to give any reason for doing so.

The aim of this interview is to try and understand your personal experience of having ended the main treatments (surgery, radiotherapy and chemotherapy) for your breast cancer. I am interested in hearing about how you felt about ending treatment, and how things have been for you since then.

The interview will be informal and you can take the lead so that you have the opportunity to talk about the issues which are most important to you. I will ask some questions to help the interview to progress, but if there is anything you do not want to answer please just let me know and we will move on.

Does this sound alright to you? Do you have any questions before we begin?

Interview Prompts

(NB – these are prompts and will not be followed verbatim, due to the semi-structured nature of the interview)

- Tell me a bit about ending your treatment for breast cancer
- How did you feel when your treatment was finished?
- Can you tell me what you did when your treatment ended?
- What (if anything) has changed in your life since your treatment ended?
 - Any physical changes?
 - Any emotional changes?
 - Any changes in your relationships?
 - Any changes in your daily activities?
- How (if at all) is your life different now to before you had breast cancer?
- Have you re-started doing daily activities you did before you had breast cancer?
- Do you feel you are getting back to 'normal life'?
- Has anything helped or hindered you being able to adjust back to 'normal life'?
- Do you think much about your experience of breast cancer?
- What are your thoughts about the future?
- How do you feel you have coped since your treatment ended?
- Have you had any contact with the medical team since you ended your treatment?

00-04

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through the chemotherapy with me all the time, but the radiotherapy I came everyday myself (yeah). And I think [consultant clinical oncologist] was quite good as well, because she said, I think you should start driving now [participant]. Because of the chemotherapy I felt as though I couldn't drive, my concentration, and I had no concentration. So I thought well this is the stage... I've got to master this basically. So coming for the radiotherapy and then meeting other people that, not for who, it wasn't breast cancer at that point, it was different kinds of cancers. But coming away from that you thought oh I'm not going to see these people again... (laughs)

I: So there was something about being with other people with cancer that was (yeah)... a support?

P: Yeah I think it was a support. And I think you felt its not only me, that feels this way. You know, that there's people ill that... Although I never felt ill through this, so you know, I felt worse actually when I had the flu at times. I never really felt ill but because you had to go all through these different, em, the chemo the operation the chemo again and then the radiotherapy. Em I think it was like a safety net, when it was the radiotherapy, you know getting the radiotherapy and saw the nurses. And then there was nothing... after that. And I think that's what the good thing with going to the physiotherapy bit as well, because it was like a well-being group in a way because you had been through everything and now you were in the next, the next stage. And then starting my work now. So for me, I think that... you know they said you're now on a journey and I can remember saying to the doctor well it's a journey I'd prefer not to go on but... I'm here now. But for me I think that was quite good, cause I don't know how I would have felt if I'd finished the radiotherapy and then just went back to work. I don't know how I would've been.

I: Can you imagine how it might have been without having the group in between?

P: I think I would have been more emotional at work. (mmhm) Just, I think, not that I've been vain or anything like that but I think I would've felt... I probably would have still been wearing my wig by now I think (right) As I say not that I would have been vain or anything

Coding Density

concentration difficulties
support from others with cancer
compare self to others
safety net of treatment
nothingness after treatment
over-protective of self
return to previous activities
experience of physio group
changes to
not vain
sadness at end of treatment
stages of recovery
not feeling ill
impact of treatment
more emotional
contact with others with cancer
journey
bridge between treatment & life
stop wearing
self-confide

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Participant1
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but, you know, it's a big thing like having loads of dark hair and then having no hair and then sprigging hair everywhere else (*gestured to face*). And it's just your appearance has changed. And I'm three stone heavier than what I was when I left work... you know...

I: So the changes to your appearance have... kind of affected you as well have they?

P: A wee bit. But not, as I say, like I've not been, was never vain.... Like I took care of myself, you know, ate well, did keep-fit, went to Pilates and made sure that I was kind of presentable and everything. But I think because I work in an office... like its lots of men, I think it was more that. More thinking, not how I felt, but thinking how they would feel when they saw me (right). So although I'm saying I'm not vain I think it was more, how... I was more thinking how other people... felt when they saw me, to be honest, rather than myself (yeah). Yeah... I would say that, yeah. It's probably came over early as if it was me, how I looked, but I would say it's more when people saw the change in me, how they would react.

I: And how have people reacted in general?

P: They've been great. When I went to work, it's really strange because it's the younger men that have come to me and said 'hi [participant] how are you? You're looking really well'. And I don't know if they're being polite or not. But it's funny cause it's me that's always mentioning my hair. Cause it's something I feel that I've got to... I don't know, I don't know if I feel I've got to say it but I think are they holding back? But nobody's said anything about my hair. (mhm). But it's the young sort of chaps that come back. And I was in work yesterday and there was a few girls, em managers from our other office and they were saying why don't you come through and speak to everybody and see them and everything like that. So you know, they want to.... But I'm still the same person, you know, it's just... you know. It's funny...

I: That's come up a few times about feeling that you are the same person, but there's been these changes as well (mhm). In what way do you feel different having ended the

increase in weight
stop wearing wig
taking care of self
see self through others reactions
self-confidence
social support
returning to work
reactions of others to change
not vain
concern how others view
changes to appearance
Coding Density

same person but d
uncertainty about self
still same person

Nodes: 204 References: 546 Read-Only Line: 156 Column: 75
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